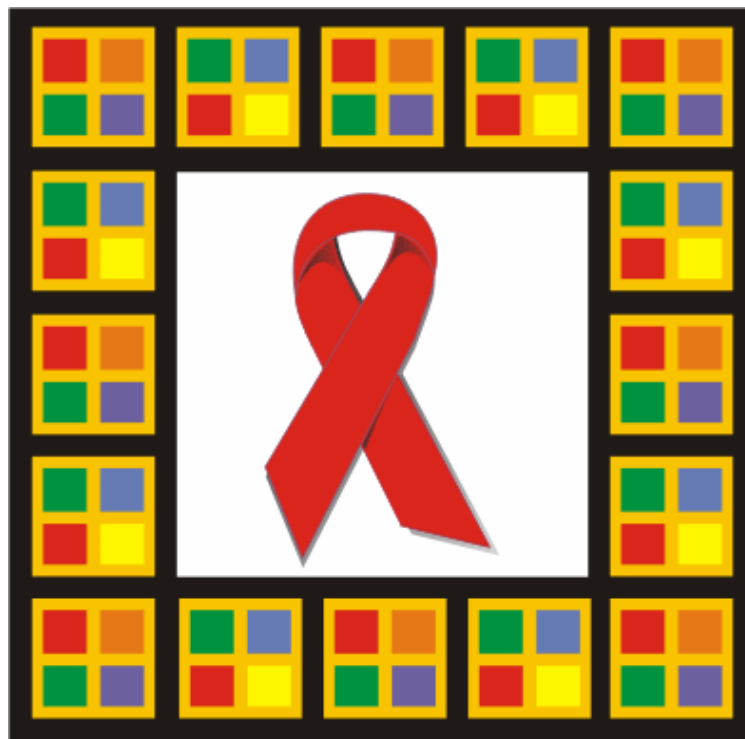


2005 Tennessee Integrated Epidemiologic Profile for HIV/AIDS Prevention and Care Planning



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EXECUTIVE SUMMARY

At the end of 2004, 12,069 persons were estimated to be living with HIV/AIDS in Tennessee, nearly 50% of whom had been diagnosed with AIDS. Currently, there are persons living with HIV/AIDS in all 95 counties of the state. Studies have shown that improved survival among persons with AIDS since 1995 was attributed primarily to the slower progression of HIV-associated immune deficiency among persons who used highly active antiretroviral therapy (HAART).¹⁻⁴ (Centers for Disease Control and Prevention, 1998; Palella FJ, Jr, et al., 1998; McNaghten AD, et al., 1999; Fleming PL, et al., 1998).

Sixteen percent of the total general population of Tennessee is African-American. The HIV/AIDS diagnosis rate for this minority group continues to be disproportionately high; in 2004, the rate was eight times higher than among Whites. During 2004, 59% of newly diagnosed HIV/AIDS cases were among African-Americans. The percentage of newly diagnosed HIV/AIDS cases reported among females in Tennessee has remained stable over the past five years, with women representing 28% of new HIV/AIDS cases in 2004.

Among Whites, male-to-male sex (MSM) was the predominant mode of exposure in 2004. Over the past 10 years, MSM exposure has declined substantially; however, behavioral data indicate that this high-risk behavior continues in all racial/ethnic groups. Among African-Americans and Hispanics, heterosexual contact was identified as the leading mode of exposure during 2004.

Although the number of women living with HIV/AIDS in Tennessee has risen, perinatal transmission rates decreased dramatically over the past decade, and remained stable over the past five years (approximately 4.5% of total perinatally-exposed infants born). The decrease in transmission rates has been attributed to screening programs for pregnant women and increased use of antiretroviral therapy in pregnant women and their infants. However, even with low transmission rates, the number of HIV-infected babies

may continue to increase as the number of babies born to HIV-infected mothers rises due to growing numbers of women living with HIV.

In a behavioral survey of high-risk populations conducted in 2002, less than half (47.7%) of persons surveyed reported that they had been tested for HIV in the last 12 months. Surveillance data on HIV testing delays indicate that some groups may not fully benefit from recent treatment advances because they are not tested early in their infections – almost three-quarters (72%) of persons during 2000-2004 who tested positive and progressed to AIDS were diagnosed with AIDS within three months of first learning of their HIV infection. Testing delays represent just one factor that may be contributing to the recent increase in AIDS cases and leveling of AIDS mortality; the recent changes in these measures were preceded by several years of decline. Other contributing factors may be limited access to or use of health services, and limitations of current therapies.

In 2004, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title II funds provided assistance to approximately 59% of persons living with HIV/AIDS in Tennessee. There did not appear to be any disparities in access to this assistance, as the sociodemographic characteristics of CARE Act clients were representative of the general HIV-positive population in Tennessee. During that same year, Ryan White CARE Act Title II funds were used primarily to provide case management, medical care, and nutritional support services. Among HIV-positive residents who participated in the 2005 Consolidated HIV/AIDS Needs Assessment Survey, approximately one out of four noted that they lacked access to dental care. Other services observed lacking included access to housing assistance, transportation, and nutritional services.

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This document was created in collaboration with the Centers for Disease Control and Prevention.

INTRODUCTION

This Epidemiologic Profile provides detailed information about the current HIV/AIDS epidemic in Tennessee. Specifically, this report describes the general population of Tennessee, HIV-infected persons living in Tennessee, and persons at risk for HIV infection. The profile is an essential resource for planning HIV/AIDS prevention and care activities throughout the state. The data presented in this report serve to guide prevention and service efforts, justify and obtain funding for the implementation of prevention and service programs, and to evaluate programs and policies throughout Tennessee. Multiple data sources were utilized to create a thorough and comprehensive document, which addresses five key questions:

1. What are the sociodemographic characteristics of the general population in Tennessee?
2. What is the scope of the HIV/AIDS epidemic in Tennessee?
3. What are the indicators of risk for HIV/AIDS in Tennessee?
4. What are the patterns of service utilization of HIV-infected persons in Tennessee?
5. What are the characteristics of persons who know they are HIV-positive but are not receiving HIV primary medical care in Tennessee?

The following report is organized around these questions. Each of the questions represents a section of the report, which includes relevant data and interpretation.

EPIDEMIOLOGIC PROFILE BACKGROUND

This profile was developed to demonstrate how to use the new integrated guidance for HIV/AIDS prevention and care planning. Previous Epidemiologic Profiles developed for the state of Tennessee focused on answering questions specific to the prevention planning process. However, this profile, in accordance with the new integrated guidelines, has been expanded to meet the needs of both prevention and care planning. Many new data sources were included to provide a comprehensive and multi-perspective profile.

PROFILE DATA SOURCES

Data were compiled from a variety of sources to provide the most complete picture possible. Each of the data sources used has strengths and limitations, which should be considered when interpreting the data. Below is a brief description of each of the data sources used in the profile. For a more detailed description of these sources, please refer to Appendix A.

1. Core HIV/AIDS Surveillance

HIV/AIDS Surveillance Data

In 1984, the Tennessee Department of Health established a surveillance system to track newly diagnosed AIDS cases. This surveillance system was expanded in February of 1993 to include confidential, name-based HIV reporting. Standardized case report forms are used; these forms collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status (i.e., living or dead), and referrals for treatment or services.

Based on state evaluations (Tennessee HIV/AIDS Program), HIV infection reporting is estimated to be >95% complete for persons who have tested positive for HIV. HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or have not sought testing. Persons who have tested positive in an anonymous, or out-of-state, test site and have not sought medical care, where they would be confidentially tested, are not included in HIV surveillance statistics. Therefore, HIV infection data can only provide minimum estimates of the number of persons purported to be HIV-infected. In addition, newly reported cases may be reported to the health department at any point along the clinical spectrum of disease when first diagnosed. Consequently, HIV infection data do not necessarily represent characteristics of persons who have been recently infected with HIV.

Enhanced Perinatal Surveillance

Perinatal HIV/AIDS surveillance is the ongoing and systematic collection of information on HIV-infected pregnant mothers and on perinatally exposed (i.e., exposed around the time of birth) and HIV-infected children. Extensive medical record abstractions are conducted for all HIV-exposed children and their mothers, and the children are followed up until their infection status is determined. These data address the prevention of perinatal transmission, and describe prenatal care, HIV counseling and testing during pregnancy, and use of zidovudine (ZDV) or other antiretroviral drugs among pregnant mothers and neonates. Also, questions regarding treatment issues for women infected with HIV and their children are answered. Enhanced perinatal surveillance data provide perinatal-specific data that can be used to determine the extent to which testing is conducted and ZDV is prescribed in clinical practice, and to identify barriers to the implementation of Public Health Service guidelines. The perinatal data may underestimate the number of mother-infant pairs, because some pregnant women may not know they are HIV-infected or have not been tested for HIV. Perinatal data include only those women who have had a positive confidential HIV test and their infants. Perinatal testing for HIV is required in Tennessee.

2. Behavioral Surveys

Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a state-based random digit-dialed telephone survey of adults that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. Respondents to the BRFSS questionnaire are asked a variety of questions about their personal health behaviors and health experiences. A sexual behavior module was added to this survey in 1994, 1995, 1996, 1998 and 2000. In this module, adults (ages 18-49) were asked about their number of sexual partners, condom use, and treatment for STDs. Data from the BRFSS survey are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state, not just persons at

highest risk for HIV/AIDS. However, since BRFSS respondents are contacted by telephone, the data are not representative of households that do not have telephones.

Youth Risk Behavior Survey (YRBS)

The YRBS is a self-administered questionnaire given every two years to a representative sample of 9th through 12th grade students at the state and local level. In Tennessee, the survey is administered at the state level within public schools. The YRBS collects information on six categories of behaviors, of which sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases (STDs), including HIV, is one. Questions are also asked about exposure to HIV prevention education materials, sexual activity (age of debut, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and pregnancy history. YRBS uses a standardized questionnaire so that comparisons can be made across participating jurisdictions. Jurisdictions may also add questions of local interest. However, the YRBS project relies upon self-reported information; therefore, reporting of sensitive behavioral information may not be accurate (under- or over-reporting may occur). Also, since the YRBS questionnaire is administered in school, the data are only representative of children who are enrolled in school and cannot be generalized to all youth. For example, students at highest risk, who may be more likely to be absent from school or to drop out of school, may be underrepresented in this survey, especially among older grade levels. The questionnaire does not ask about homosexual or bisexual behavior.

3. STD Surveillance

STD Case Reporting

The Tennessee Department of Health HIV/STD/AIDS Section conducts statewide surveillance to determine the number of reported cases of STDs and to monitor trends. Other services include partner counseling and, to help reduce the

spread of STDs, referral services for examination and treatment. In Tennessee, chancroid, chlamydia, gonorrhea, lymphogranuloma venereum, and syphilis are reportable STDs. STD surveillance data can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of changes in a specific behavior (e.g., rates of rectal gonorrhea). STD data are widely available at the state and local level. Because of shorter incubation time periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (i.e., ulcerative STDs) can facilitate transmission and/or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms, such as unprotected sex. Some STDs are reportable, but requirements for reporting vary across states. Reporting of STDs from private sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk.

4. HIV Counseling and Testing Data

Counseling and Testing System (CTS)

The Tennessee Department of Health conducts HIV CTS services at 141 different sites across Tennessee. These locations include STD, family planning, prenatal and tuberculosis clinics, drug treatment centers, community-based organizations (CBOs), county health units, community health centers, and mobile test sites. The CTS collects information on counseling and testing services delivered and the characteristics of clients receiving the services, such as demographics, risk information, and testing information (testing history, test result). All sites within Tennessee offer confidential testing only. CTS provides standardized data on clients who are tested for HIV, which may offer insights into HIV infection rates in an area's high-risk population. CTS collects information only from persons who seek counseling and testing services or agree to be tested after consultation at one of the publicly funded sites. Therefore, estimation of HIV

statewide seroprevalence is not possible with CTS data because the clients self-select for testing.

5. Substance Abuse Data

The *Tennessee Outcomes for Alcohol and Drug Services (TOADS)* project was a study based on five calendar year admissions (1998-2002) to publicly funded alcohol and drug abuse treatment facilities. Data was collected upon admission to publicly funded facilities in Tennessee and was compiled by the Tennessee Bureau of Alcohol and Drug Abuse Services, a unit of the Tennessee Department of Health. This project is conducted in collaboration with the University of Memphis, who carries out monitoring and outcome evaluation research.

Respondents are asked a standardized set of questions about types and frequency of drug use, and data collected includes gender, race, age, residence type (urban or rural), and pregnancy status. Care should be used when interpreting this data as it reflects only those patients admitted to publicly funded alcohol and drug abuse treatment facilities. Thus, these data may not accurately reflect specific sub-populations within Tennessee.

6. Vital Statistics Data

Birth and Death Data

The National Center for Health Statistics receives information on births and deaths in the U.S. through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. States use standard forms to collect birth and death data. The birth certificate form collects newborn, maternal, and paternal demographics; insurance status; prenatal care; prenatal risk factors; maternal morbidity; mode of delivery; pregnancy history; and clinical characteristics of the newborn. Death certificates capture the demographics,

underlying cause of death, and contributions of selected factors to the death (i.e., smoking, accident, or injury) of all deceased persons. Reporting is approximately 100% complete for both births and deaths. Therefore, inferences can be made concerning the number of live births in a service area. The data can also be used to determine the impact of deaths related to HIV infection in a service area. Birth certificate data are often not complete for data that are obtained from patient medical records (i.e., smoking history, morbidity). In addition, deaths resulting from, or whose underlying cause was, HIV infection, may be under-reported on a death certificate. Clinical information related to HIV or AIDS may be missing. In Tennessee, death records are less timely than AIDS case reports.

7. Population Data

U.S. Bureau of the Census (Census Bureau)

The Census Bureau collects and provides timely information about the people and economy of the U.S. The Census Bureau's website, located at <http://www.census.gov>, includes data on demographic characteristics (e.g., age, race, Hispanic ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the percentage of persons who live at or below the poverty level. Summaries of the most requested information for states and counties are provided, as well as analytical reports on population changes, age, race, family structure, and apportionment. State and county-specific data are easily accessible, and links to other census information websites are included.

Health Information Tennessee (HIT)

This website is administered by the State of Tennessee's Office of Health Statistics. The website includes current population estimates and projections; economic, income and poverty status information; demographic profiles and rankings; and census geography. Information is available for the state, counties, cities, and metropolitan areas. County population trends are also provided. Links

to state census data center local affiliates and to other census information websites are included as well. The website can be located at: <http://hit.state.tn.us>.

8. Ryan White CARE Act Data

Title I and II Statewide HIV/AIDS Needs Report

Every three years, grantees of Ryan White Title I and Title II programs administer a detailed survey to Tennessee residents, including persons living with HIV/AIDS. The purposes of the survey are to gain a greater understanding of the current level of HIV/AIDS service needs and to provide insight into consumers' perceptions of the availability and quality of HIV/AIDS care and prevention efforts throughout the state. A uniform survey instrument was employed that included a variety of demographic identifiers (e.g., age, race, gender, residence type, education level, income source, and locale) and HIV-related care/prevention questions (e.g., primary care requirements, risk behaviors, co-morbidities, types of health insurance coverage, and prevention information). From across the state a convenience sample was selected consisting of people who frequented general businesses, places of worship, educational institutions, and bars/clubs; clients encountered in primary care clinics, including social service agencies, community health centers, substance abuse or mental health treatment facilities, homeless or transitional shelters, and correctional facilities; and persons who were approached via street outreach. Respondents were not required to complete the questionnaire in full. All returned questionnaires were entered into the database for analysis.

Because the survey was administered to a non-scientific sample, response distributions may not be reflective of the statewide population as a whole. In addition, response omissions could potentially limit the usefulness of affected questions. Thus, discretion should be observed before drawing definitive conclusions. Regardless of these limitations, however, beneficial insights can be realized that will allow planners to better focus resource allocation for HIV care and prevention services.

Ryan White Title I CAREWare

Since 1993, the HIV/AIDS Program of the Tennessee Department of Health has collected data on persons served through Tennessee Ryan White Title I funding. In late 1999, the HIV/AIDS Drug Assistance Program (HDAP) data collection system was expanded into a more comprehensive database that was named Tennessee CAREWare. This database includes key information on all persons receiving assistance through any of the Ryan White Title II funded programs, as well as through State Formula Housing Opportunities for People with AIDS (HOPWA) funds. In order to be eligible for Ryan White Title II services a person must be living with HIV/AIDS, be a resident of the State of Tennessee, and have an income that is equal to or less than 200% of the current year's Federal Poverty Level (FPL). Information collected from service providers throughout the state includes basic demographic and risk information on each of the clients, eligibility verification data (current address, current income, HIV diagnosis, and Tennessee TennCare number), the type of services received, the date and quantity of services received, the cost of these services, and other pertinent information (history of substance abuse or mental health treatment, veteran status, current pregnancy status [women only]). CAREWare is an important tool for monitoring which Ryan White resources are being utilized, how often and by whom. However, the data captured in Tennessee CAREWare cannot be generalized to all HIV-infected persons living in this state, since the data collected are only for persons who (1) know their HIV serostatus; (2) are not eligible for health coverage through private insurance or Tennessee TennCare; (3) are currently seeking care and treatment services through Ryan White Title II-funded providers; and (4) are financially eligible to receive services.

PROFILE STRENGTHS AND LIMITATIONS

It is important to consider the overall strengths and limitations of this document when making planning decisions. Although the profile is comprehensive and draws from a number of different data sources, there are many things that the profile cannot explain.

While the HIV/AIDS surveillance system in Tennessee is extensive, it is based only on those people who have been tested confidentially for HIV. Consequently, HIV infections are under-detected and under-reported because only persons with HIV who choose to be tested confidentially are counted. Also, persons are tested at variable times following HIV infection and many individuals are not tested until they have progressed to AIDS. Thus, it is important to remember that the data in this report do not necessarily represent characteristics of persons who have been recently infected with HIV, nor do they provide a true measure of HIV incidence.

Analyses of many different data sets have been presented in this report to provide robust representations of particular subpopulations. However, demographic and geographic subpopulations are disproportionately sensitive to differences and changes in access to health care, HIV testing patterns, and targeted prevention programs and services. All of these issues must be carefully considered when interpreting HIV data. Therefore, it is important to make comparisons across data sources to get the most complete picture.

The most current analysis available is presented for each source of data; however, the most recent data collected varies from one source to another. In addition, more detailed analyses are available for some sources. Although a limited number of analyses were available from the Bureau of the Census at the time this profile was prepared, that agency expanded its race/ethnic reporting categories in 2000. The information presented in this report is for statewide planning, but some regional data are presented. Detailed regional information is available within regional HIV/AIDS profiles, as well as on the Tennessee Center's of Excellence website, located at: <http://www.coetenn.com>.

PROFILE PREPARATION

This profile was prepared by the Tennessee Department of Health HIV/AIDS/STD Surveillance and Data Management Program in close collaboration with the Tennessee Ryan White CARE Act and Prevention Programs and the Centers for Disease Control and Prevention (CDC). The Tennessee STD Program provided direct guidance on the use and interpretation of STD (non-HIV) data, and BRFSS data were provided by the Tennessee BRFSS program. The Internet was utilized as much as possible to obtain needed data. Sociodemographic data, vital statistics, substance abuse data and YRBS information were all downloaded from Internet sites. Several of the Internet sources compile their data from other organizations and agencies – such as Kaiser Family Foundation (for insurance information) and HRSA (for the CARE Act Data Report [CADR]).

Throughout this report the following statistical methods were used in order to measure the impact of the epidemic upon specific populations, adjust for delays in reporting, and account for cases with missing risk information:

- Case rates were calculated for the 12-month period per 100,000 population. For these rates, denominators were derived from the 2000 Census. The numerator is the number of cases diagnosed during the 12-month period.
- When HIV/AIDS data are presented as trends, the data are "adjusted" to account for reporting delay for recently diagnosed cases. Reporting delay refers to the period of time between when a case is diagnosed and when the report of the case is received by the health department. Cases recently diagnosed may not have had adequate time to be reported; therefore, for recent time periods, the number of cases diagnosed but not yet reported, is estimated and presented as "expected" cases. The methods used to estimate the numbers of these cases are discussed in the glossary under "reporting delay."

- Regarding "missing risk information," cases that have been recently diagnosed are more likely to be reported without a specified risk (exposure). To provide data on reclassification of risk over time, the cases with missing risk information must be assigned to one of the risk categories. Cases with missing risk information are distributed to a risk category based on regional sex- and race-specific risk probabilities provided by the CDC. Consequently, data adjusted for risk redistribution represent the expected number of cases within each risk category. For example, the adjusted number of cases in the IDU exposure group in 2001 would be the sum of (a) the number of cases diagnosed in 2001 where injection drug use was the risk factor and (b) the number of cases diagnosed in 2001 without risk information but where injection drug use is assigned as the likely risk factor.
- The Bureau of the Census, in compliance with the Office of Management and Budget Directive 15 (OMB 15), expanded race/ethnicity reporting in 2000. The expanded questionnaire allowed respondents to select one or more races to indicate their racial identity. However, for comparisons with HIV/AIDS data for which information on only one race and Hispanic ethnicity is collected, the race/ethnicity data obtained from the Bureau of the Census were combined into six categories: White, non-Hispanic; Black, non-Hispanic; Hispanic; American Indian/Alaska Native, Asian/Pacific Islander, and Unknown/Multiple Race.

ORGANIZATION OF THE PROFILE

The epidemiologic profile is organized into two main sections, within which the five key questions are addressed:

Section 1: Core Epidemiologic Questions

This section of the report provides the reader with an understanding of the characteristics of the general population in Tennessee, the distribution of HIV disease, and a detailed look at persons at risk for HIV infection. The section is organized around three key questions:

Question 1: What are the Sociodemographic Characteristics of the General Population in Tennessee?

Orients the reader to the overall demographic and socioeconomic characteristics of the general population of Tennessee.

Question 2: What is the Scope of the HIV/AIDS Epidemic in Tennessee?

Examines the impact of the HIV/AIDS epidemic among a number of population groups in Tennessee, to help planners target prevention and care services.

Question 3: What are the Indicators of Risk for HIV/AIDS in Tennessee?

Provides a detailed look at high-risk populations. Both direct measures of risk behaviors associated with HIV transmission and indirect measures that may serve as indicators of high-risk behavior are examined in this segment.

Section 2: Ryan White HIV/AIDS CARE Act- Special Questions and Considerations

This section focuses on questions that pertain to Health Resources and Services Administration (HRSA) HIV/AIDS care planning groups. Section two provides a description of access to, utilization of, and standard of care among persons in Tennessee who are HIV-positive. It is organized around two key questions:

Question 4: What are the Patterns of Service Utilization of HIV-Infected Persons in Tennessee?

Characterizes the patterns in the use of services by a number of the populations living with HIV/AIDS in the state of Tennessee. Information is provided from HRSA-funded programs as well as supplemental studies that examine specific aspects of HIV care in Tennessee.

Question 5: What are the Characteristics of Persons Who Know They are HIV-Positive but are not Receiving HIV Primary Medical Care in Tennessee?

Describes studies currently underway in Tennessee to assist in assessing the unmet need of persons who know they are HIV-positive, but who are not in care. Presents special studies that query persons living with HIV/AIDS about their service needs and perceptions of care in Tennessee.

Question 1: What are the Sociodemographic Characteristics of the General Population in Tennessee?

This section provides information on the demographic and socioeconomic characteristics of the state. Regional Epi-Profile Tables, which are available at <http://www.coetenn.com>, describe each region in more detail.

Population: In 2004, the total population for Tennessee was an estimated 5,990,962 persons. The state is comprised of 95 counties. County populations ranged from a low of 4,881 persons in Pickett County to a high of 908,175 in Shelby County. The metropolitan regions of Shelby, Davidson, Knox, Hamilton, Madison and Sullivan Counties represented 41% of Tennessee's total population. In descending order by population size, the major cities are Memphis, Nashville, Knoxville, Chattanooga, Clarksville, and Murfreesboro, with populations ranging approximately from 671,929 to 81,511. Overall, the state has 10 Metropolitan Statistical Areas (MSAs). (*Source: U.S. Census Bureau*)

Consortia/Planning Group Regional Structure: The Tennessee Department of Health is divided into eleven distinct geographic regions; Northeast Region, East Region, Upper Cumberland Region, Mid-Cumberland Region, West Region, Sullivan County, Knox County, Chattanooga/Hamilton County, Nashville/Davidson County, Madison County, and Memphis/Shelby County. There are five multi-county geographic regions for planning and provision of services; East, Southeast, Middle, West, and Southwest. Each of the consortia/planning regions is comprised of one or more health department regions.

Demographic Composition: Based on U.S. Census projected 2004 data, the racial and ethnic composition of the state was estimated to be 80% White and 16% African-American; Asians, Native Americans, Native Hawaiians, and other races comprised the

remaining 4%. Individuals of Hispanic origin were estimated to be up to 2.9% of the total population. (Source: *U.S. Census Bureau*)

Age and Sex: In 2004, the median age for Tennessee residents was 37 years of age. Persons age 5 years and younger represented 7% of the total population, while 76% of the population was over age 18. Furthermore, 12% of the total population was age 65 or older. The percentage of females in the overall population was slightly higher than the percentage of males (51% versus 49%). (Source: *U.S. Census Bureau*)

Poverty, Income, and Education: For 2002-2004, the median household income in Tennessee was \$38,550. According to 2002-2003 data from the *Kaiser Family Foundation*, nearly 1,066,670 residents (18% of the population) for whom poverty status was determined had incomes that fell below the 100% poverty level, compared to 17% nationally. Of Tennessee's children 18 years or younger, 26% were living in poverty in 2002-2003. Fifty-four percent (54%) of low-income families in Tennessee are headed by a single parent (Source: *National Center for Children in Poverty*), and 11.6% of all families had incomes below the poverty level. The unemployment rate in 2005 was 5.5 percent statewide versus 5.0 percent nationwide. In 2002-2003, there were 695,950 uninsured individuals in Tennessee. Of these individuals, 556,040 were adults age 19-64, which represents 15% of the total population in Tennessee. In 2004, 81% of Tennessee residents age 25 years and older reported educational attainment of high-school graduate or higher. (Source: *U.S. Census Bureau*)

Health Indicators: It was recently reported in *Health State Facts Online by the Kaiser Family Foundation* that prenatal care in Tennessee ranks 34th with only 82.8% (nationwide was 83.7%) of the mothers receiving prenatal care in their first trimester for year 2002. In 2001, the state was 8th in the rate of infant mortality (8.7 infant deaths per 1,000 live births). Tennessee ranked the 11th highest in 2002 with the rate of births to teens (54.3 per 1,000 live births versus the national teen birth rate 43.0) and 13th in the number of low birth weight babies (9.2% of live births). According to the *Health State Facts Online by the Kaiser Family Foundation*, Tennessee had the 8th highest number of

reported syphilis cases per 100,000 populations and the 12th highest ranking in the United States for gonorrhea in 2003. Gonorrhea cases were reported as 147 per 100,000 persons versus 116 nationally. Lastly, the *Kaiser Family Foundation* indicated that many persons in Tennessee go to hospital emergency rooms for medical care in lieu of a primary care physician, with Tennessee ranking 7th nationally in the number of emergency outpatient visits to hospitals.

Public Aid: In 2004, 1,332,597 (23%) of Tennessee residents were covered by TennCare and 622,266 children under the age of 20 relied on TennCare for their health needs, *TennCare Eligibles, Bureau of TennCare, 2004*. Medicare covered 855,278 (15%) individuals in 2002. (*Source: Centers for Medicare and Medicaid Services*)

DEMOGRAPHICS

In 2004, the population of the State of Tennessee was 5,897,306 persons. The largest proportion of the population was age 35-44 years. The age distribution among males and females under 65 years was similar. Above 65 years of age, however, the percentage of women was 4% greater than among men (Table 1).

Table 1. Percentage distribution of the general population, by age group and sex, Tennessee, 2004

Age Group (Years)	Male, % (N=2,877,844)	Female, % (N=3,019,462)	Total Population, % (N=5,897,306)
<10	14.0	12.7	13.3
10-14	7.3	6.6	7.0
15-24	14.3	13.1	13.7
25-34	14.2	13.4	13.8
35-44	15.1	14.8	14.9
45-54	14.3	14.4	14.4
55-64	10.4	10.6	10.5
>=65	10.3	14.4	12.2

Source: Tennessee Bureau of Health Statistics

Table 2. Percentage distribution of the general population, by race/ethnicity and sex, Tennessee, 2004

Race/Ethnicity	Male, % (N=2,877,844)	Female, % (N=3,019,462)	Total Population, % (N=5,897,306)
White, non-Hispanic	82.0	81.0	81.5
Black, non-Hispanic	16.3	17.4	16.8
Hispanic	3.4	2.2	2.8
Other	1.7	1.7	1.7

Source: Tennessee Bureau of Health Statistics

The collection of race and ethnicity information was expanded in the 2000 Census to allow persons the opportunity to report belonging to more than one race group, as well as to report Hispanic ethnicity. In 2004, 3.4% of males and 2.2% of females comprised of all races reported themselves as Hispanic (Table 2). Males and females comprised 48.8% and 51.2% of the state's population, respectively.

Table 3. Percentage distribution of the general population by race/ethnicity and consortia region, Tennessee, 2004

Consortia Region	Race/Ethnicity				Total Population
	White, non-Hispanic, %	Black, non-Hispanic, %	Hispanic, %	Other, %	
Southwest	50.0	48.2	3.3	2.4	1,006,815
West	80.1	19.2	1.8	0.7	533,450
Middle	85.5	12.4	3.8	2.1	2,170,026
Southeast	86.4	12.1	2.0	1.4	618,981
East	95.0	3.9	1.6	1.1	1,568,034

Source: Tennessee Bureau of Health Statistics

The Southwest consortium region holds the state's highest percentage of African-Americans (48.2%), while the East consortium region has the smallest percentage (3.9%). The percentage of Whites was greater than 80% in all consortia regions except for the Southwest region, where the percentage was 50%. Additionally, the proportion of Whites and African-Americans is very similar within the Southwest region. The Middle consortium region has the highest percentage of persons reporting themselves as Hispanic (3.8%).

Table 4. Percentage distribution of the general population, by race/ethnicity for counties of >250,000 population compared with population of Tennessee, 2004

Race/Ethnicity	Population, %				
	Davidson (N=587,279)	Hamilton (N=311,334)	Knox (N=393,486)	Shelby (N=921,268)	Statewide (N=5,897,306)
White, non-Hispanic	69.1	77.5	89.1	47.1	81.5
Black, non-Hispanic	27.1	20.6	8.9	50.4	16.8
Hispanic	6.0	2.1	1.5	3.5	2.8
Other	3.8	1.9	2.0	2.5	1.7

Source: Tennessee Bureau of Health Statistics

According to the 2004 Tennessee Bureau of Health Statistics, the distribution of race/ethnicity varied across Tennessee counties that have a population of more than 250,000 (Table 4). In Shelby County, the state's most populous county, one-half of the population (50.4%) indicated their race as African-American, compared to approximately one-fourth (27.1%) in Davidson County, one-fifth (20.6%) in Hamilton County, and less than one-tenth (8.9%) in Knox County. Statewide, less than 2% of the population reported their race as "Other". The percentages of persons in these four counties that identify as Other ranged from 3.8% to 1.9%. In Davidson County, 6.0% of the population identify themselves as Hispanic, compared with 2.8% statewide.

Table 5. Percentage distribution of persons living below the poverty level by sex and age group, for counties of >250,000 population, Tennessee, 2000

Age Group	Living Below Poverty Level by Gender, %							
	Davidson		Hamilton		Shelby		Statewide	
	Male, % (N=30,994)	Female, % (N=39,966)	Male, % (N=15,059)	Female, % (N= 21,249)	Male, % (N=59,408)	Female, % (N=80,990)	Male, % (N=343,869)	Female, % (N=472,907)
<25	56.7	47.1	53.3	41.6	60.7	49.4	54.6	44.5
25-44	25.0	27.3	22.6	25.3	21.8	26.9	20.4	25.7
45-64	12.8	13.9	16.7	16.8	12.4	13.4	16.9	17.5
≥65	5.5	11.7	7.4	16.3	5.1	10.3	8.1	12.3

Source: Census 2000, US Bureau of the Census, and Tennessee Census Data Center Profile.

In 2000, persons less than age 25 years comprised the highest proportion of those who lived below the poverty level, both statewide and within the most populous counties (Table 5). Nearly half of all Tennesseans who were living below the poverty level, 54.6% of males and 44.5% of females, were in this age group. Among those age 25 and older

living below the poverty level, females constituted the higher proportion (55.5%) in comparison to males (45.4%). This disparity extended statewide, as well as in Davidson, Hamilton, and Shelby Counties.

Table 6. Percentage distribution of the population 25 years and older by educational attainment and sex, for counties of >250,000 population, Tennessee, 2000

Education	Educational Attainment by Gender, %							
	Davidson		Hamilton		Shelby		Statewide	
	Male, % (N=178,444)	Female, % (N=199,290)	Male, % (N=96,181)	Female, % (N=110,999)	Male, % (N=255,985)	Female, % (N=302,071)	Male, % (N=1,774,566)	Female, % (N=1,970,362)
< 9th grade	5.9	5.6	5.8	6.1	6.2	5.6	9.9	9.3
Some high school	13.1	12.4	12.8	13.7	13.3	13.3	14.6	14.4
High school diploma/GED	23.6	25.6	25.7	28.5	25.4	26.9	30.9	32.2
Some college, no degree	21.0	22.0	23.3	23.6	22.9	25.1	19.5	20.6
Associate or bachelor's degree	25.1	24.9	23.0	21.1	22.3	21.0	17.7	17.5
Graduate or professional degree	9.4	8.7	8.1	6.4	8.5	7.6	6.3	5.7

Source: Census 2000, US Bureau of the Census 2000 Summary File 3.

The most frequently reported level of maximal educational achievement in Tennessee among adults age 25 years and older, regardless of location or gender, was the high school diploma (or equivalent). Statewide, this constituted 30.9% of men and 32.2% of women (Table 6).

Among persons age 25 years and older, approximately three-quarters of the men and women (74.4% and 76.0%, respectively) in Tennessee have earned a minimum of a high school diploma/GED. Among counties with populations exceeding 250,000 persons, this proportion approaches four out of five adults. In Davidson County, Shelby County, and statewide, slightly higher percentages of females as compared to males had completed high school or attended college; in Hamilton County this gender trend was reversed. Higher percentages in Davidson County among both men (55.5%) and women (55.6%) reported as having pursued higher education in comparison to those in Hamilton County, Shelby County, or statewide. Alternately, among counties with greater than 250,000 residents, Davidson County had lower percentages of both men (5.9%) and

women (5.6%) who attained less than a 9th grade education as compared to those in Hamilton County, Shelby County, or statewide.

Question 2: What is the Scope of the HIV/AIDS Epidemic in Tennessee?

The HIV/AIDS epidemic has affected persons in every gender, age, and racial/ethnic group in Tennessee. In the beginning of the epidemic, HIV/AIDS cases rose most sharply among White men who reported having sex with other men (MSM). Recent trends suggest a shift in the HIV/AIDS epidemic towards women, minorities, and high-risk heterosexuals (HRH). As the epidemic continues to evolve, and the number of persons living with HIV/AIDS continues to increase, it will be important to identify those populations most impacted or most at risk for HIV/AIDS infection. This will allow agencies to develop effective HIV/AIDS prevention and care activities, as well as to allocate limited resources to those people who need it most.

This section provides detailed information about demographic and risk characteristics of HIV/AIDS infected individuals, and includes five-year cumulative data pertaining to trends in the statewide epidemic. This document also describes estimated cumulative cases diagnosed through 12/31/2004 by year of diagnosis, age of diagnosis, exposure category, gender, and race/ethnicity. Unless noted, all data originates from Tennessee's HIV/AIDS Surveillance Program and includes only Tennessee residents at time of HIV/AIDS diagnosis. Numbers shown in tables within this section represent estimates resulting from CDC statistical data-smoothing. Consequently, values displayed in each column may not necessarily sum to the column total.

Highlights

- There are persons living with HIV/AIDS in every county of Tennessee, and the number continues to increase each year. At the end of 2004, 12,069 persons were estimated to be living in the state with HIV/AIDS.
- The annual number of newly diagnosed AIDS cases in Tennessee appears to have peaked, with incidence remaining stable over the past three years. This follows a marked rise in incidence that occurred between 2001 and 2002.

- New HIV/AIDS diagnoses among Black, non-Hispanics continue to be disproportionately high. In 2004, 59% of newly diagnosed HIV/AIDS cases were among the Black, non-Hispanic population.
- Among White, non-Hispanic males, MSM is the predominant mode of exposure in 2004. In contrast, heterosexual contact was the most frequently cited mode of exposure among Black, non-Hispanic and Hispanic populations.
- The percentage of newly diagnosed HIV/AIDS cases reported among females in Tennessee has increased steadily since the beginning of the epidemic; women represented 28% of new HIV/AIDS cases in 2004.
- Perinatal transmission rates have remained stable from 2000 through 2004, due to screening programs for pregnant women and increased use of antiretroviral therapy in pregnant women and their infants.

Overall HIV/AIDS Trends

During 2004, Tennessee had an estimated 1,108 newly diagnosed cases of HIV/AIDS. These numbers reflect persons with HIV/AIDS infection whose positive status was first diagnosis and reported to the health department. Presently, the estimated cumulative number of reported HIV/AIDS cases in the Tennessee HIV/AIDS Registry stands at 18,685 (Table 8).

Due to reporting delays from HIV/AIDS infection to diagnosis, some persons may have been diagnosed with AIDS at the time HIV was first diagnosed. In recent years, the number of diagnosed cases, including the number of expected cases, has remained stable. Reporting delays were estimated using a maximum likelihood procedure, taking into account possible differences in reporting delays among exposure, geographic, ethnic, age, and gender categories. The methods used to estimate the numbers of these cases are discussed in the glossary under “Reporting Delay.”

Table 7. Estimated HIV/AIDS cases among persons in Tennessee, by year of diagnosis and sex

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Sex	No.	No.	No.	No.	No.	No.
Males	769	728	788	768	802	14,529
Females	322	284	306	272	306	4,156
Total	1,091	1,012	1,094	1,040	1,108	18,685

During the period 2000-2004, the estimated number of persons diagnosed in Tennessee with HIV/AIDS continued to be over 1,000 cases per year but appears to have leveled off. As has occurred since the beginning of the epidemic, the number of new HIV/AIDS cases reported annually remained consistently higher among males. But during this period the relative increase in newly diagnosed HIV/AIDS cases varied significantly across genders. Cases involving males increased 36% since the beginning of 2000. In contrast, the number of new cases reported among females decreased 5% during this period (Table 7).

Table 8. Estimated HIV/AIDS cases among persons in Tennessee, by year of diagnosis and race/ethnicity

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Race/ethnicity	No.	No.	No.	No.	No.	No.
White, not Hispanic	361	360	384	359	392	8,167
Black, not Hispanic	696	630	662	634	658	10,060
Hispanic	24	16	34	36	49	348
Asian/Pacific Islander	4	4	4	8	1	45
American Indian/Alaska Native	0	1	1	0	1	14
Unknown/Multiple Race	5	1	8	3	6	51
Total	1,091	1,012	1,094	1,040	1,108	18,685

As previously stated, HIV/AIDS was initially viewed as a White, male-oriented disease, but over time it has spread across gender, race, and ethnic boundaries. Currently, the highest prevalence of HIV/AIDS cases in Tennessee is among the Black, non-Hispanic population; this group accounts for over 60% of all cases diagnosed between 2000 and 2004. This disparity is further compounded by considering the population of Tennessee as a whole. According to the latest U.S. Census statistics, Black, non-Hispanics account for 16% of the state's population but comprise 54% of the cumulative HIV/AIDS cases diagnosed in Tennessee. In contrast, White, non-Hispanics account for almost 80% of the population but 44% of the state's HIV/AIDS cases. Hispanics and all other non-Hispanic populations (Asian/Pacific Islander, American Indian/Alaskan Native, Unknown/Multiple Race) account for 4% of the total population and 2% of the total reported HIV/AIDS cases (Table 8).

More research needs to be conducted to explain the disproportionate numbers of cases among the Black community, but some studies have suggested that possible causes include lack of health care access, the reinforced stigma of HIV/AIDS disease within this community, or inadequate prevention messages directed to this minority group.

Table 9. Estimated HIV/AIDS cases among persons in Tennessee, by year of diagnosis and age at diagnosis

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Age (yrs)	No.	No.	No.	No.	No.	No.
<13	6	7	4	7	5	155
13-14	2	1	1	1	0	19
15-24	184	167	152	179	174	2,644
25-34	340	258	341	292	316	7,309
35-44	375	346	347	340	355	5,728
45-54	128	176	175	162	191	2,069
55-64	46	44	59	46	54	589
>=65	9	13	14	14	12	173
Total	1,091	1,012	1,094	1,040	1,108	18,685

During the course of this epidemic, the majority of persons diagnosed with HIV/AIDS in Tennessee have been between ages 25 and 44 years. Cumulatively, 7,309 HIV/AIDS cases were diagnosed in people in the age group 25-34 years, and 5,728 cases were diagnosed among persons in the age group 35-44 years. During the period 2000-2004, annual incidence was relatively stable among persons age 35-44 years. However, data for the five year period suggests a trend in the number of cases decreasing among those 34 years of age and younger while increasing among those 45 years of age and older (Table 9). This evidence suggests that the HIV/AIDS epidemic may have begun to spread to older populations.

Table 10. Estimated HIV/AIDS cases among persons in Tennessee, by year of diagnosis and exposure category

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Exposure category	No.	No.	No.	No.	No.	No.
Male-to-male sex	517	507	558	544	563	9,910
Injection drug use (IDU)	130	98	100	102	115	2,722
Male-to-male sex and IDU	33	29	22	35	29	944
Heterosexual contact	397	361	402	349	386	4,679
Mother with/at risk for HIV/AIDS	5	7	4	6	5	129
Other	8	9	6	5	10	300
Total	1,091	1,012	1,094	1,040	1,108	18,685

At the onset of the epidemic in the early 1980s, HIV/AIDS was thought to be acquired primarily through male-to-male intercourse. This idea was perpetuated because the first cases of this disease were identified among White, non-Hispanic males whom reported having sex with other men (MSM). As additional information of the disease became available, and testing for the virus became possible, an increased number of cases began to be reported among Black, non-Hispanic males. Presently, HIV/AIDS in Tennessee continues to be a predominantly male disease, with over 50% of reported HIV/AIDS cases (annually and cumulatively) being attributed to MSM. The second highest category of risk is heterosexual contact, which has been increasing among both males and females (Table 10).

HIV/AIDS by Demographic/Exposure Categories

The category of exposure (i.e., persons' risks for HIV/AIDS transmission) has changed in recent years. Throughout the epidemic, most HIV/AIDS transmission has occurred due to male-to-male sex (MSM). More recently, the proportion of cases among individuals exposed to HIV/AIDS through heterosexual contact with a person with, or at increased risk for, HIV/AIDS infection (e.g., injection drug user [IDU]), especially among females, has been increasing.

The largest proportion of cases diagnosed in 2004 (51%) were attributed to MSM, after adjusting for reporting delays. Cases of MSM, including MSM/IDU, accounted for 53% of all new cases diagnosed in 2004 (Table 10); furthermore, more than half (56%) of all persons living with HIV/AIDS in Tennessee may have been exposed to the virus through MSM contact (Table 18). Heterosexual contact was implicated in 35% of current cases and 29% of all living cases. Injection drug users (IDU) remain a high risk group as well, accounting for 10% of newly diagnosed cases and 13% of all living cases.

The 2004 statewide HIV/AIDS infection rate was estimated as 18.8 people/100,000 population. As previously stated, large disparities exist when comparing the prevalence of HIV/AIDS infection by race/ethnicity. According to the current data, Black, non-Hispanics have the highest rates of HIV/AIDS infection of any racial/ethnic group in Tennessee. In the current year, Black, non-Hispanics have infection rates of 67.3/100,000 – a figure almost eight (8) times higher than that reported among White, non-Hispanics and almost two (2) times higher than Hispanics. Rates among males were significantly higher than those among females (27.9 versus 10.1 per 100,000, respectively). In general, rates calculated from small numbers of cases, such as those reported among Asian/Pacific Islanders or American Indian/Alaskan Natives, should be evaluated carefully as they may lead to inaccurate deductions on the current state of the epidemic (Table 11).

**Table 11. Estimated HIV/AIDS cases and rates (per 100,000 population)
in Tennessee, by sex and race/ethnicity, 2004**

Race/ethnicity	Males			Females			Total		
	No.	%	Rate	No.	%	Rate	No.	%	Rate
White, not Hispanic	317	40	13.8	75	24	3.1	392	35	8.3
Black, not Hispanic	441	55	95.9	217	71	41.9	658	59	67.3
Hispanic	39	5	51.3	10	3	19.8	49	4	38.4
Asian/Pacific Islander	0	0	0	1	0	3.1	1	0	1.6
American Indian/Alaska Native	0	0	0	1	0	13.5	1	0	6.6
Unknown/Multiple Race	4	1	a	2	1	a	6	1	a
Total	802	100	27.9	306	100	10.1	1,108	100	18.8

a - Not applicable.

**Table 12. Estimated HIV/AIDS cases in Tennessee,
by exposure category and race/ethnicity, 2004**

Exposure Category	White, not Hispanic		Black, not Hispanic		Hispanic		Asian/Pacific Islander		American Indian/ Alaska Native		Unknown/ Multiple Race		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Male-to-male sex	259	66	282	43	19	39	0	0	0	0	3	50	563	51
Injection drug use (IDU)	42	11	66	10	6	12	0	0	0	0	0	0	115	10
Male-to-male sex and IDU	18	5	11	2	1	2	0	0	0	0	0	0	29	3
Heterosexual contact	68	17	290	44	22	45	1	100	1	100	3	50	386	35
Mother with/at risk for HIV/AIDS	0	0	4	1	1	2	0	0	0	0	0	0	5	0
Other	5	1	5	1	0	0	0	0	0	0	0	0	10	1
Total	392	100	658	100	49	100	1	100	1	100	6	100	1,108	100

In 2004, there were 1,108 estimated new cases of HIV/AIDS diagnosed in Tennessee. By race/ethnicity, 59% of the cases were among Black, non-Hispanics, 35% among White, non-Hispanics, 4% among Hispanics, and <1% among other racial/ethnic populations. While the overall number of new cases implicating exposure by MSM has been increasing over past five years, heterosexual contact has emerged among Black, non-Hispanics and Hispanic populations as the leading exposure category, accounting for 44% and 45% of all newly diagnosed cases, respectively. Among White, non-Hispanics, the predominant mode of exposure remained MSM (66%) followed by heterosexual contact (17%). IDU was the third most common risk category among White, non-Hispanics, Black, non-Hispanics, and Hispanics racial/ethnic groups (Table 12).

Table 13. Estimated HIV/AIDS cases among persons in Tennessee, by sex and exposure category, 2004

Exposure category	Males		Females		Total	
	No.	%	No.	%	No.	%
Male-to-male sex	563	70	a	a	563	51
Injection drug use (IDU)	71	9	43	14	115	10
Male-to-male sex and IDU	29	4	a	a	29	3
Heterosexual contact	131	16	255	83	386	35
Mother with/at risk for HIV/AIDS	2	0	3	1	5	0
Other	5	1	5	2	10	1
Total	802	100	306	100	1,108	100

a - Not applicable.

As previously stated, males comprise the largest percentage of estimated HIV/AIDS cases in Tennessee. The most frequently reported exposure category among males in 2004, numbering 563 cases, was male-to-male sex (MSM), which accounted for 70% of the 802 estimated new HIV/AIDS cases within this gender. The number of males exposed through heterosexual contact was 131 (16%), followed by injection drug use numbering 71 (9%) cases. For females, the largest exposure category was through heterosexual contact with 255 cases (83%) of the total 306 estimated new HIV/AIDS cases, followed by 43 cases (14%) from injection drug use (Table 13).

Table 14. Estimated HIV/AIDS cases among persons in Tennessee, by sex and age at diagnosis, 2004

Age (yrs)	Males		Females		Total	
	No.	%	No.	%	No.	%
<13	2	0	3	1	5	0
13-14	0	0	0	0	0	0
15-24	115	14	59	19	174	16
25-34	222	28	94	31	316	29
35-44	275	34	79	26	355	32
45-54	139	17	52	17	191	17
55-64	38	5	16	5	54	5
>=65	9	1	3	1	12	1
Total	802	100	306	100	1,108	100

Among persons diagnosed with HIV/AIDS in 2004, 355 individuals (32%) were in the age group 35-44 years, and 316 people (29%) were between the ages of 25-34 years. Less than 2% of the estimated cases combined were among children under age 13 years and in adults greater than or equal to age 65 years. By gender, 34% of males diagnosed with HIV/AIDS this year were in the age group 35-44 years, while 31% of females diagnosed were in the age group 25-34 years (Table 14).

Persons Living with HIV/AIDS by Year

Persons affected by HIV/AIDS are counted in several different ways. In the previous tables, persons were tabulated by the year in which they were diagnosed, age of diagnosis, race/ethnicity, gender, and exposure category. The following tables denote persons living with HIV/AIDS at the end of a specified year and do not include those patients whom have died. As of 12/31/2004, 12,069 persons were estimated to be living with HIV/AIDS in Tennessee. In actuality, this number is underestimated because it excludes HIV/AIDS infected persons who have not yet been tested or who have only been tested anonymously. To account for individuals who have not yet been tested, this

value should be inflated by about one-quarter to one-third, according to the CDC (Fleming PL, et al., 1998).

Table 15. Estimated number of persons living with HIV/AIDS in Tennessee, by year and sex

	2000	2001	2002	2003	2004
Sex	No.	No.	No.	No.	No.
Males	7,505	7,941	8,363	8,699	9,046
Females	2,399	2,571	2,746	2,873	3,023
Total	9,904	10,512	11,109	11,571	12,069

During the period 2000-2004, there were approximately three times as many males than females living with HIV/AIDS in Tennessee. Continued HIV/AIDS infections and newly diagnosed cases among males have caused the number in this population to increase 21% from 7,505 persons in 2000 to 9,046 in 2004. Among females, HIV/AIDS prevalence has risen 26% from 2,399 persons in 2000 to 3,023 in 2004 (Table 15). The current data illustrates a growing trend of HIV/AIDS infection within the female population that can be attributed to increased exposure via heterosexual contacts.

Table 16. Estimated number of persons living with HIV/AIDS in Tennessee, by year and race/ethnicity

	2000	2001	2002	2003	2004
Race/ethnicity	No.	No.	No.	No.	No.
White, non-Hispanic	4,238	4,464	4,691	4,868	5,108
Black, non-Hispanic	5,446	5,811	6,136	6,393	6,614
Hispanic	163	176	208	236	270
Asian/Pacific Islander	23	27	31	39	38
American Indian/Alaska Native	6	7	8	8	9
Unknown/Multiple Race	28	28	36	27	28
Total	9,904	10,512	11,109	11,571	12,069

Increases in the number of persons living with HIV/AIDS were also demonstrated in each racial/ethnic category. An estimated 55% of the people currently living with

HIV/AIDS in Tennessee are Black, non-Hispanic; approximately 42% are White, non-Hispanic, 2% are Hispanic, and the remaining 1% is distributed among Asian/Pacific Islanders, American Indian/Alaska Natives and Unknown/Multiple Race (Table 16).

Table 17. Estimated number of persons living with HIV/AIDS in Tennessee, by year and current age

	2000	2001	2002	2003	2004
Current age (yrs)	No.	No.	No.	No.	No.
<13	57	64	68	75	81
13-14	10	10	10	9	9
15-24	170	224	305	423	572
25-34	1,827	2,004	2,223	2,438	2,650
35-44	4,337	4,531	4,712	4,803	4,953
45-54	2,629	2,753	2,831	2,860	2,872
55-64	700	748	776	777	765
>=65	176	178	183	186	168
Total	9,904	10,512	11,109	11,571	12,069

At the end of 2004, the majority of persons (87%) living with HIV/AIDS were in the age group 25-54 years. Those age 24 years or younger comprised just 5% and adults age 55 years and older comprised only 8%, respectively, of all living cases (Table 17).

Table 18. Estimated number of persons living with HIV/AIDS in Tennessee, by year and exposure category

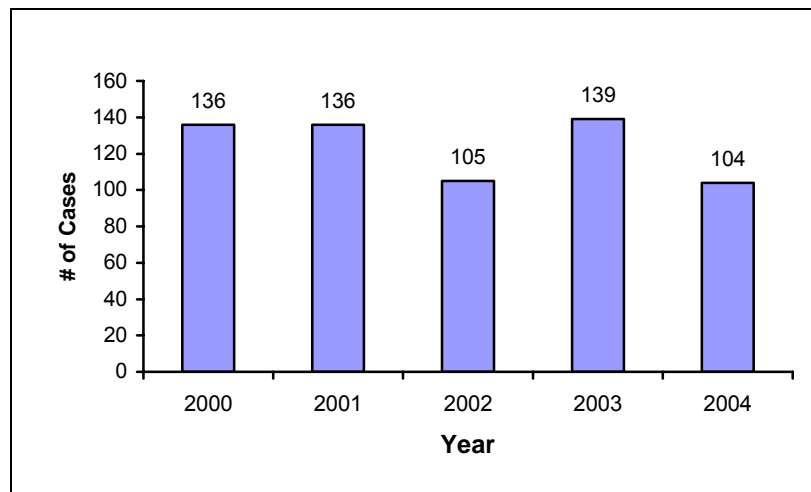
	2000	2001	2002	2003	2004
Exposure category	No.	No.	No.	No.	No.
Male-to-male sex	5,035	5,365	5,704	5,998	6,286
Injection drug use (IDU)	1,624	1,635	1,647	1,617	1,613
Male-to-male sex and IDU	482	490	485	487	487
Heterosexual contact	2,560	2,805	3,058	3,248	3,452
Mother with/at risk for HIV/AIDS	81	88	92	97	102
Other	123	128	123	125	129
Total	9,904	10,512	11,109	11,571	12,069

Among those individuals living with HIV/AIDS at the end of 2004, the exposure category MSM accounted for over half (52%) of individuals statewide. Heterosexual contact was the second highest category of exposure in 29% of all living cases, and the third most frequent category of exposure was among injection drug users, who comprised 13% of those people living with HIV/AIDS (Table 18).

HIV/AIDS Perinatal Exposure

Perinatal transmission has dropped dramatically from 1995 to 2004, with the introduction and widespread use of antiretrovirals during pregnancy and labor and delivery. Since 2000, the number of babies born to HIV/AIDS infected mothers has also leveled off. Infants born to HIV infected mothers are followed by case workers for up to 18 months from their date of birth. At the conclusion of the 18-month period babies are classified as: HIV-positive, AIDS-positive, or seroreverters (not having the HIV/AIDS virus). Due to the lag-time from birth to actual diagnosis, the total number of infants diagnosed with HIV or AIDS tends to be deflated in the current year. A total of 28 (4.5%) of the 620 perinatally-exposed infants born in Tennessee during 2000-2004 were ultimately diagnosed with HIV infection, of which two (2) were diagnosed with perinatal AIDS.

Figure 1: Perinatally Exposed HIV/AIDS Cases in Tennessee, 2000-2004



While HIV perinatally-exposed infants were reported from most metropolitan areas in 2004, the majority of cases were reported from Memphis/Shelby County (58%) and Nashville/Davidson County (13%). Additionally, of the 104 HIV perinatally-exposed infants reported in 2004, approximately 77% were among Black, non-Hispanics. This trend is historically consistent over the period from 2000-2004, and these statistics strongly suggest that interventions focusing on pregnant females should encourage women to seek prenatal care and treatment early in their pregnancies.

AIDS Trends and HIV/AIDS Mortality

New highly active antiretroviral therapies (HAART) were introduced in 1996. These drugs have been shown to be effective in the treatment of HIV/AIDS infection and, since that time, have altered the natural progression of HIV/AIDS infection. HAART has delayed the progression from HIV/AIDS to AIDS and from AIDS to death for many people infected with HIV/AIDS. Due to the widespread use of these HIV/AIDS treatments, there have been declines seen nationwide in the number of AIDS-related deaths. For this reason, AIDS surveillance data no longer accurately represent trends in HIV/AIDS transmission. Rather, AIDS surveillance data now reflect differences in access to testing and treatment, as well as the failure of certain treatment regimens. Consequently, AIDS incidence and deaths, from 1996 on, provide a measure for identifying and describing the populations for whom treatment may have not been previously accessible or effective.

AIDS Trends

During 2004, Tennessee had an estimated 767 newly diagnosed cases of AIDS. These numbers reflect persons infected with the HIV virus who had progressed to present with clinical manifestations of AIDS and were reported to the health department. Presently, the estimated cumulative number of reported cases of AIDS in the Tennessee HIV/AIDS Registry stands at 11,272 (Table 20).

Table 19. Estimated AIDS cases among persons in Tennessee, by year of diagnosis and sex

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Sex	No.	No.	No.	No.	No.	No.
Males	452	471	586	544	580	9,209
Females	173	179	186	208	186	2,064
Total	625	650	771	753	767	11,272

The estimated number of new AIDS cases diagnosed appears to have peaked, following a marked rise occurring between 2001 and 2002. Annual incidence and relative increases in diagnosed AIDS cases have varied significantly between genders since 2000. As has occurred since the beginning of the epidemic, the number of new AIDS cases reported annually remained consistently higher among males (Table 19).

Table 20. Estimated AIDS cases among persons in Tennessee, by year of diagnosis and race/ethnicity

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Race/ethnicity	No.	No.	No.	No.	No.	No.
White, non-Hispanic	204	212	264	259	264	5,285
Black, non-Hispanic	405	425	480	468	464	5,719
Hispanic	12	8	17	20	32	201
Asian/Pacific Islander	3	0	2	3	0	21
American Indian/Alaska Native	0	1	0	0	0	10
Unknown/Multiple Race	1	3	9	3	6	37
Total	625	650	771	753	767	11,272

During the period 2000-2004 the estimated number of new AIDS cases tended to increase annually in all of Tennessee's largest race/ethnic groups. Since the beginning of 2000, prevalence of AIDS increased 64% among Black, non-Hispanics. Cumulatively, this population now comprises 51% of total reported AIDS cases. White, non-Hispanics comprise the second highest volume of reported AIDS cases at 47% of the cumulative

total, while Hispanics and other minority populations represent only 2% of total cases reported (Table 20).

Table 21. Estimated AIDS cases among persons in Tennessee, by year of diagnosis and age at diagnosis

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Age (yrs)	No.	No.	No.	No.	No.	No.
<13	0	0	1	0	1	56
13-14	0	0	0	0	0	4
15-24	46	45	47	38	52	658
25-34	191	170	208	188	202	4,130
35-44	251	246	297	320	301	4,166
45-54	105	142	160	162	150	1,667
55-64	26	34	46	36	44	454
>=65	6	12	13	9	16	138
Total	625	650	771	753	767	11,272

Cumulatively, 74% of reported cases were in the age group 25-44 years when initially diagnosed with AIDS. Of particular interest during the period 2000-2004 was the observable increase in the frequency of Tennesseans age 35 years and older (Table 21). Possible explanations could include (1) that these data may signify a delay in the onset of AIDS due to increased availability of highly active antiretroviral treatment among the HIV positive population, or (2) an increased number of people diagnosed with AIDS are waiting until symptoms of the disease exist before testing for HIV. In any case, the AIDS population within Tennessee appears to be getting older.

The highest cumulative reported exposure category among AIDS cases statewide was MSM, numbering 6,279 (56%) of the total. Among estimated AIDS cases diagnosed in the period 2000-2004, MSM was also the most frequent exposure category reported annually. Heterosexual contact was the second most frequently reported exposure category associated with AIDS, consisting of 2,296 (20%) of the total cases. Annually, the incidence of AIDS cases acquired through heterosexual contact has increased, and

this may indicate a gradual shift in the epidemic from traditional MSM and IDU transmissions (Table 22).

Table 22. Estimated AIDS cases among persons in Tennessee, by year of diagnosis and exposure category

	2000	2001	2002	2003	2004	Cumulative cases through 2004
Exposure category	No.	No.	No.	No.	No.	No.
Male-to-male sex	280	313	398	367	388	6,279
Injection drug use (IDU)	116	100	113	122	118	1,729
Male-to-male sex and IDU	29	24	28	29	32	684
Heterosexual contact	196	208	227	228	221	2,296
Mother with/at risk for HIV/AIDS	0	0	1	0	1	47
Other	4	6	4	7	6	236
Total	625	650	771	753	767	11,272

Morbidity Trends

One of the most devastating effects of HIV/AIDS is how the virus affects a person's immune system. As the immune system is compromised, the patient becomes highly susceptible to contracting numerous communicable diseases. If left untreated, this could result in injury or death.

Table 23. Estimated HIV/AIDS cases among persons in Tennessee, by sex and tuberculosis co-morbidity, 2004

	Males		Females		Total	
Tuberculosis diagnosis	No.	%	No.	%	No.	%
Not diagnosed	796	99	304	99	1,100	99
Definitive case	5	1	2	1	7	1
Presumptive case	0	0	0	0	0	0
Total	802	100	306	100	1,108	100

Tuberculosis (TB) is one such disease spread through microscopic bacteria (germs) that can float in the air. These germs are generally passed from people with active TB disease through coughing and sneezing. The steady decline in incidence of TB dating from 1953 was seen to reverse in 1985, coinciding with the expansion of the AIDS epidemic.

For HIV/AIDS patients that have impaired immune systems, contracting TB disease is much more likely. It has also been suggested that TB in immunocompromised patients tends to be a more aggressive disease. If a patient has symptoms of TB infection (excessive coughing, coughing up of mucus or blood, chest pain when coughing), then a TB test should be performed by a clinician to rule out TB disease. This disease is curable, and several medications are used to treat TB in patients currently receiving antiretroviral therapy. In Tennessee, seven (7) TB cases were diagnosed among those with HIV/AIDS in 2004 (Table 23).

Mortality Trends

Data released from the Tennessee Department of Health's Surveillance and Data Management Section counts patients with HIV/AIDS that have died within a certain year, as well as cumulative deaths as of a specific date. It is very important for the reader to note that these counts do not reflect "deaths due to HIV/AIDS." This is a common misconception and can lead to incorrect conclusions if mortality trends are used improperly. Within the Tennessee HIV/AIDS Registry, a patient's vital status is recorded in one of two ways: Alive or Deceased. At this time, the database has no place to record the specific cause of death of an individual patient. Death certificates contain information about the specific causes of death, but caution should be used when interpreting these types of data. Personal biases, misdiagnoses, and other mistakes made by attending medical staff may result in an inaccurate recording of the actual cause of death. Additionally, increased investigations of death certificates by health department staff have yielded more complete information concerning a patient's death status within the HIV/AIDS database. Thus, these activities may have some impact on the trends shown in the next few tables.

Table 24. Estimated number and rates (per 100,000 population) of deaths among persons with HIV/AIDS in Tennessee, by sex and race/ethnicity, 2004

Race/ethnicity	Males			Females			Total		
	No.	%	Rate	No.	%	Rate	No.	%	Rate
White, non-Hispanic	121	27	5.3	31	20	1.3	152	25	3.2
Black, non-Hispanic	317	70	69.0	119	76	23.0	436	71	44.6
Hispanic	10	2	13.8	5	3	9.2	15	3	11.9
Asian/Pacific Islander	0	0	0	2	1	5.2	2	0	2.7
American Indian/Alaska Native	0	0	0	0	0	0	0	0	0
Unknown/Multiple Race	5	1	a	0	0	a	5	1	a
Total	454	100	15.8	156	100	5.2	610	100	10.3

a - Not applicable.

In 2004, there were an estimated 610 deaths among persons infected with HIV/AIDS in Tennessee. Black, non-Hispanics had the largest number with 436 (71%) deaths, White, non-Hispanics comprised 152 (25%) deaths, Hispanics had a total of 15 deaths (3%), and 7 deaths were reported among persons in the remaining populations (Table 24). Higher mortality rates among Black, non-Hispanics may be related to limited access to health care or resources, but may also be associated with other dynamics, such as socioeconomic or medical factors (e.g., poverty, homelessness, hypertension, etc.) which disproportionately affect this population.

Table 25. Estimated number of deaths among persons with HIV/AIDS in Tennessee, by year of death and sex

	2000	2001	2002	2003	2004	Cumulative deaths through 2004
Sex	No.	No.	No.	No.	No.	No.
Males	282	293	365	433	454	5,483
Females	69	112	131	145	156	1,133
Total	351	405	496	578	610	6,616

HIV/AIDS mortality is presently on the rise in Tennessee. Of the 6,616 estimated cumulative deaths to date, more than one-third (37%) of these have occurred within the

past five years. Mortality among persons infected with HIV/AIDS is highest among males, and this is understandable, as males have historically comprised the majority of cases in the state. Through the end of 2004, eighty-three percent (83%) of total deaths among HIV/AIDS infected patients have been recorded among males. Even though deaths among male HIV/AIDS cases increased 50% since the beginning of 2000, mortality involving female patients increased 126% during this same period (Table 25).

Table 26. Estimated number of deaths among persons with HIV/AIDS in Tennessee, by year of death and race/ethnicity

	2000	2001	2002	2003	2004	Cumulative deaths through 2004
Race/ethnicity	No.	No.	No.	No.	No.	No.
White, non-Hispanic	128	135	157	182	152	3,058
Black, non-Hispanic	214	266	337	377	436	3,445
Hispanic	4	3	3	7	15	77
Asian/Pacific Islander	1	0	0	0	2	7
American Indian/Alaska Native	2	0	0	0	0	5
Unknown/Multiple Race	2	1	0	12	5	23
Total	351	405	496	578	610	6,616

Deaths among HIV/AIDS patients have occurred in all of Tennessee's racial and ethnic groups. As recently as 2002, the majority of total deaths had occurred among White, non-Hispanic cases. But current information now indicates that cumulative mortality has occurred most frequently among Black, non-Hispanics patients (52%). It is clear from the data that there has been a rapidly expanding increase of mortality in the HIV/AIDS infected members of this minority population during the past five years. To put this in perspective, mortality among White, non-Hispanics increased 33% since 2000. In contrast, the number of deaths reported involving Black, non-Hispanics grew a disproportionate 90% during this same period (Table 26).

Table 27. Estimated number of deaths among persons with HIV/AIDS in Tennessee, by year of death and age at death

	2000	2001	2002	2003	2004	Cumulative deaths through 2004
Age (yrs)	No.	No.	No.	No.	No.	No.
<13	1	0	0	0	0	32
13-14	0	0	0	1	0	2
15-24	8	21	9	10	15	179
25-34	89	81	88	90	100	1,959
35-44	119	163	193	245	209	2,551
45-54	89	99	143	165	185	1,295
55-64	37	24	49	54	70	431
>=65	7	18	14	13	31	167
Total	351	405	496	578	610	6,616

Cumulatively, 68% of deaths among people with HIV/AIDS have occurred among persons age 25-44 years. However, the majority of deaths over the past five years (66%) have occurred in people between the ages of 35-54 years. Proportionately, there was a sizable increase in mortality incidence during this period among HIV/AIDS patients in higher age groups (Table 27).

Table 28. Estimated number of deaths among persons with HIV/AIDS in Tennessee, by year of death and exposure category

	2000	2001	2002	2003	2004	Cumulative deaths through 2004
Exposure category	No.	No.	No.	No.	No.	No.
Male-to-male sex	166	178	220	249	275	3,624
Injection drug use (IDU)	67	87	88	132	118	1,109
Male-to-male sex and IDU	31	20	28	33	30	457
Heterosexual contact	84	116	149	159	181	1,227
Mother with/at risk for HIV/AIDS	1	0	0	1	0	27
Other	2	4	11	4	6	172
Total	351	405	496	578	610	6,616

Cumulatively, the majority (55%) of the 6,116 deaths occurred in those individuals whose exposure category was MSM, 19% occurred among those infected from heterosexual contact, and 17% among those infected through injection drug use (Table 28).

Question 3: What are the Indicators of Risk for HIV/AIDS in Tennessee?

Persons most likely to become infected with HIV are those who engage in high-risk behaviors with persons that live in communities with high HIV prevalence. Thus, the following section examines the trends and characteristics of populations practicing high-risk behaviors in Tennessee, to help community-planning groups understand the varying risks for HIV infection in Tennessee.

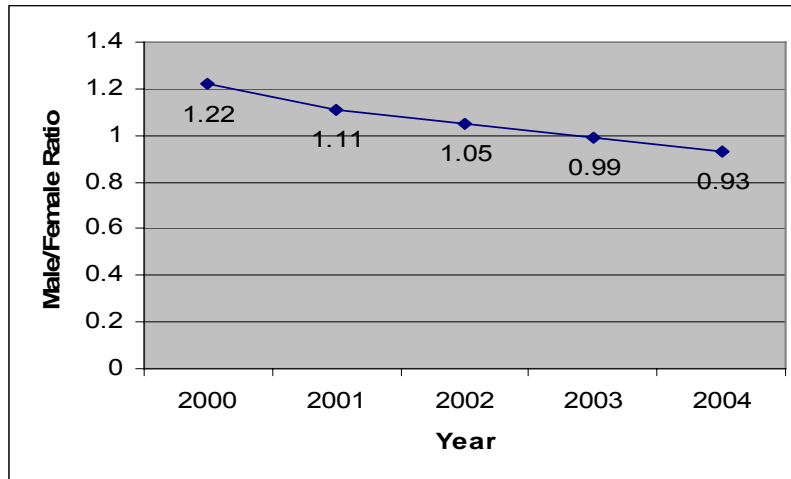
The previous section addressed the level of HIV infection in various groups affected by HIV. This section examines measures of risk behavior in the groups most at risk for acquiring HIV infection. As all of these data reflect indirect measures (data is not specifically gained from specific target populations), they do not directly describe HIV risk behaviors; however, they serve as indicators of possible HIV risk that may need further investigation. For example, an increase in STD or teen pregnancy rates does not directly indicate that HIV exposure is increasing, but may indicate an increase in unprotected sex. As standardized data from provider surveys become available later this year, their results will be included in this profile.

Highlights

- STD rates in general have decreased over the past five years. However, rates of sexually transmitted disease among minority populations are considerably higher when compared to rates among White, non-Hispanics.
- A behavioral survey of high-risk populations indicates that less than half (47.7%) of the persons surveyed reported that they had been tested for HIV in the past year.

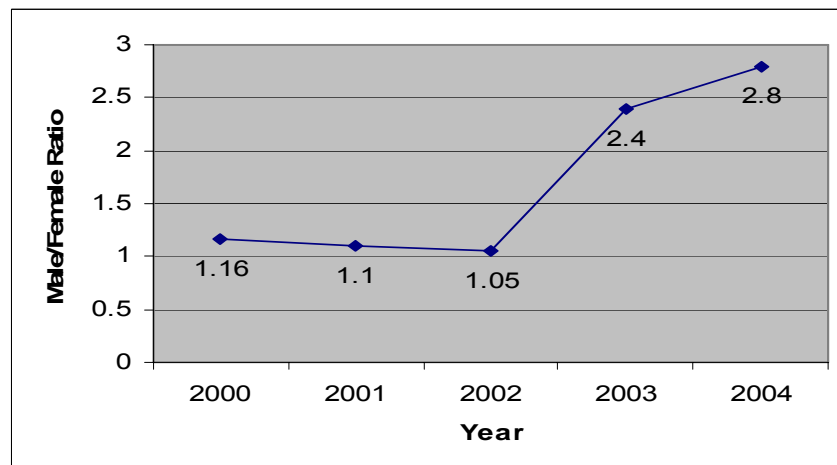
Among all people infected or at risk for HIV infection, STD surveillance data may provide information to identify the potential occurrence of high-risk behavior.

Figure 2: Trends in Male/Female Ratios of Gonorrhea, Tennessee, 2000-2004



One indirect measure that can indicate increasing rates of infections among MSM is the male/female ratio of gonorrhea or syphilis in a particular area. In Tennessee, between 2000 and 2004, the male/female ratio of gonorrhea decreased significantly (Figure 2). The ratio was highest in 2000, when there were 1.22 cases of gonorrhea among men for every case among women. At the end of 2004, the proportion of male/female cases was almost equal (0.93). While these data do not indicate an increasing trend in gonorrhea among MSM, they do indicate an increase in the proportion of reported gonorrhea cases among women.

Figure 3: Trends in Male/Female Ratios of Primary & Secondary Syphilis, Tennessee, 2000-2004



The male/female ratio of primary and secondary syphilis had decreased from 1.16 in 2000 to 1.05 in 2002 (Figure 3). However, in 2003, this ratio sharply increased to 2.4 male cases for every female case. The male/female ratio continued to increase to 2.8 in 2004. This increase was a result of outbreaks of syphilis among MSM throughout Tennessee; in fact, according to analyses conducted by the Tennessee Department of Health's Surveillance and Data Management Section, 85% of all primary and secondary syphilis cases among MSM in 2003 were also co-infected with HIV. As syphilis infection begins with a series of sores (chancres) and rashes, this disease provides a direct path for HIV to enter the human body. This is a dangerous trend that has been observed in major metropolitan areas throughout the United States, (San Francisco, New York City, Miami, and now, Tennessee) and indicates that MSM need to be educated on the risks of acquiring syphilis, as well as the risks of unprotected sexual intercourse.

STD Surveillance data and Vital Statistics data on teen pregnancy rates provide information that may help to identify the potential occurrence of high-risk behaviors. Although increases in STD or teen pregnancy rates do not directly indicate that HIV exposure is increasing, these measures may indicate an increase in unprotected sex.

Sexually Transmitted Disease Rates

Gonorrhea

Figure 4: Trends in Gonorrhea Rates by Sex, Tennessee, 2000-2004

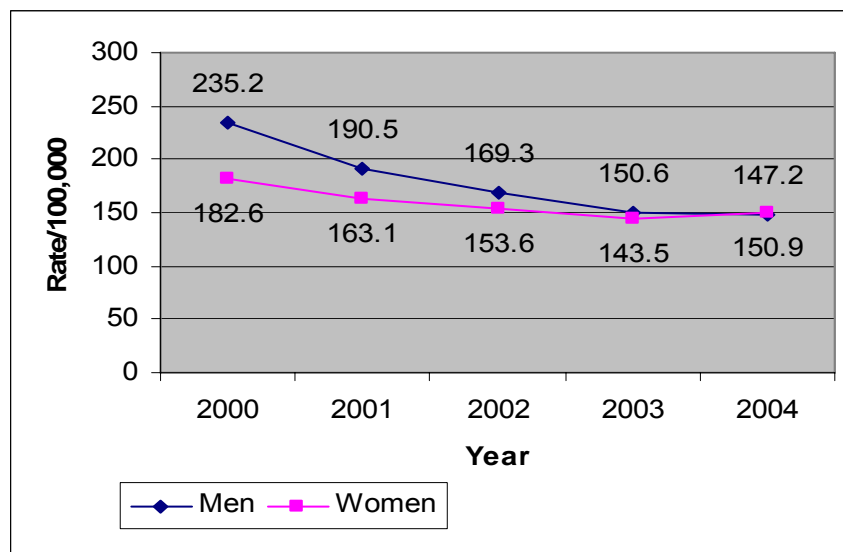
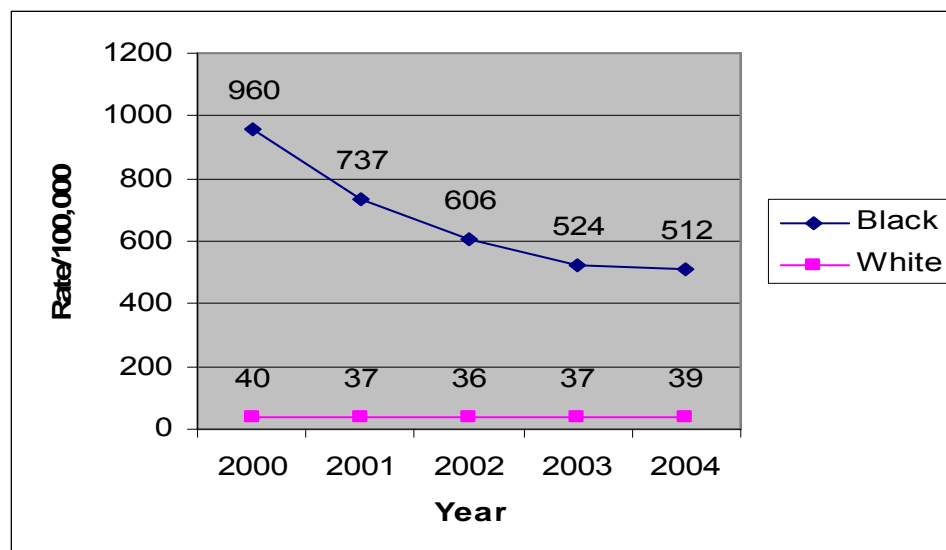


Figure 5: Trends in Gonorrhea Cases by Race/Ethnicity, Tennessee, 2000-2004



Between 1999 and 2003, gonorrhea rates were consistently higher in males compared to females (Figure 4). However, in 2004, gonorrhea rates were higher in females than males. While the rate among males continued to decrease, the female rate experienced an increase. In 2004, gonorrhea rates among Blacks were approximately 13 times greater than Whites. While rates among Whites were stable over this period, corresponding rates among Blacks decreased significantly.

Syphilis

Statewide, in 2004, 133 persons were reported with primary or secondary syphilis, which represented a 75% decrease from cases reported in 2000. Cases were reported in 16 of the 95 counties and were concentrated primarily in the Memphis/Shelby metropolitan area. During the past four years, rates of primary and secondary syphilis have been higher in males than in females (Figure 6). However, syphilis rates have decreased significantly since 1998 among both males and females. This decrease may be due, in part, to enhanced outreach, screening, and partner-notification activities as part of Tennessee's CDC-funded "Syphilis Elimination Project."

Figure 6: Trends in Syphilis Rates by Sex, Tennessee, 2000-2004

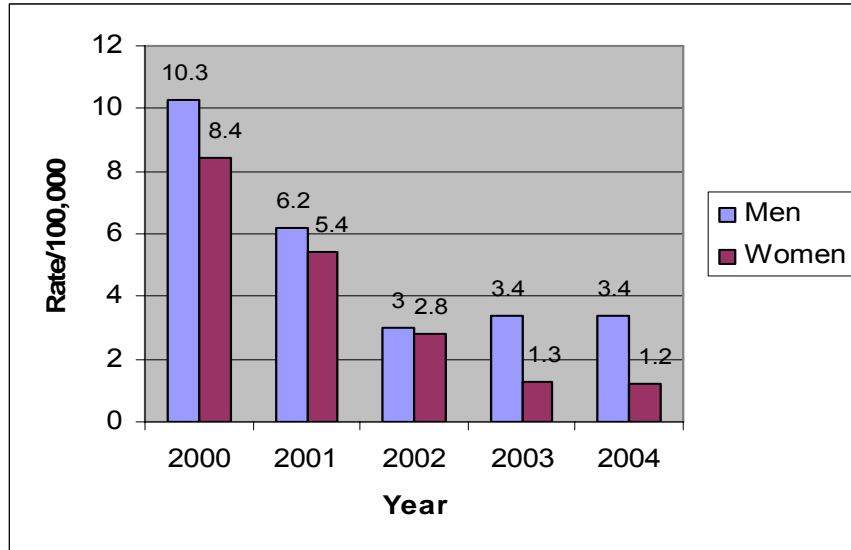
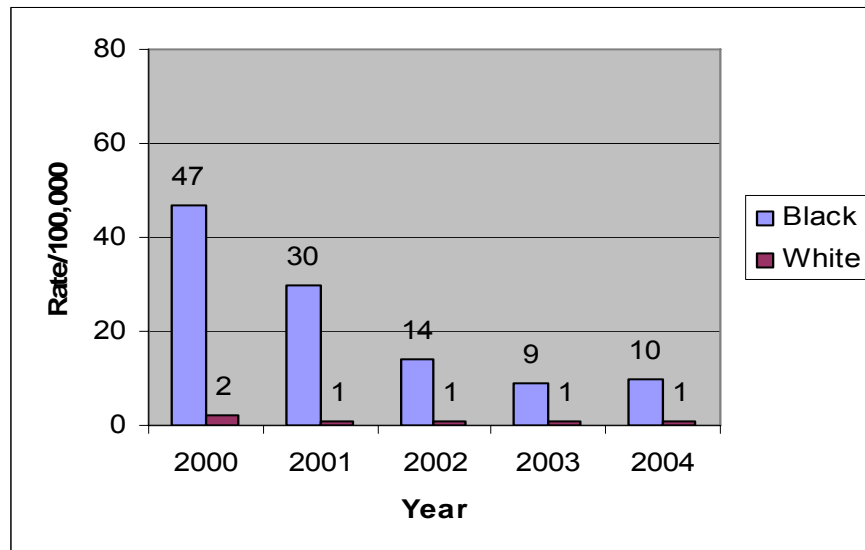


Figure 7: Trends in Syphilis Rates by Race, Tennessee, 2000-2004

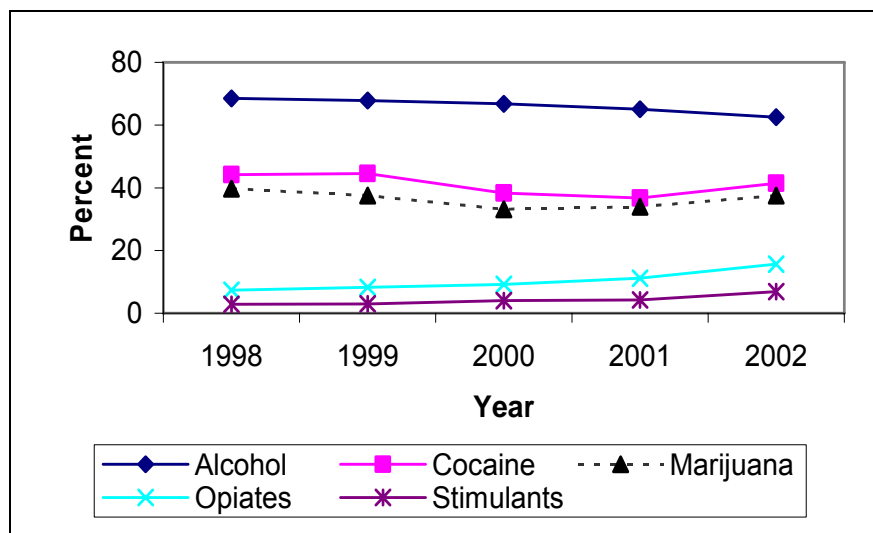


Historically, rates of syphilis in Tennessee have been much higher among Blacks than among Whites; however, the disparity in rates has narrowed in recent years (Figure 7). In 2000, rates were 23.5 times higher in Blacks compared to Whites. In 2004, rates were 10 times higher in Blacks. Rates in both groups have decreased during the past five years.

Substance Use

Among the general population in Tennessee interviewed in the *Tennessee Outcome for Alcohol and Drug Services (TOADS) Project*, Alcohol is the most commonly abused drug among participants surveyed in 2002. The percentage of clients reporting abuse of alcohol slightly declined over the course of the study (Figure 8). Rates for cocaine and marijuana also declined over the same period, but reported use of opiates (such as heroin, morphine, and oxycontin) doubled from 7.41% in 1998 to 15.63% in 2002. Additionally, use of stimulants, including amphetamines, methamphetamines, and speed increased significantly from 2.85% in 1998 to 6.85% in 2002.

Figure 8: Five-Year Substance Abuse Patterns in Tennessee



Other key findings of this study indicated:

- Females are more likely to abuse opiates and stimulants than males.
- Alcohol abuse decreased among all race groups.
- Cocaine is the most commonly abused substance by Black participants, while opiate abuse increased most significantly among Whites.
- Nearly 67% of adolescents reported using marijuana in 2002, the last year of the study.

- Rural clients abused opiates more than urban clients.
- For the first four years of the study, cocaine was the most commonly abused substance by pregnant women, but stimulant abuse rose dramatically 2002, the last year of the study.

For more information on this project, please visit the TOADS website at:

<http://www.toads.memphis.edu/reports>.

Teen Pregnancy Rates

Between 1998 and 2003, overall teen pregnancy rates decreased by 28 percent (Table 30). Black teens have experienced a greater decrease in pregnancy rates, as compared to White teens: 26% decrease among White versus 37% decrease among Blacks). Pregnancy rates in Black teens continue to be over twice as high as rates in White teens.

Table 29: Trends in adolescent (10-17 years) pregnancy rates by ethnicity, Tennessee, 1998-2003

	1998	1999	2000	2001	2002	2003
All Races	19.2	17.5	16.6	15.1	14.1	13.9
White	14.4	13.4	13.2	12.2	10.9	10.6
Black	37.7	33.2	30.6	27	25.5	25.4

Source: The Health of Tennessee Women, 2003

HIV Testing

Data on HIV testing patterns provide information that is helpful in targeting HIV counseling and testing programs. The data may also be used to help identify potential gaps in HIV surveillance data, which represent only persons who have been tested for HIV infection. HIV testing data are available from surveys conducted in the general population (Behavioral Risk Factor Surveillance System [BRFSS]) and from publicly funded HIV counseling and testing sites.

Testing at Publicly Funded Counseling and Testing Sites (Tennessee Counseling and Testing Program)

Currently, Tennessee has 141 organizations that provide publicly funded HIV counseling and testing services. These sites include Tennessee Health Department clinic sites, including Office for Addictive Disorder clinics (drug treatment centers), local health department clinics (STD, family planning, prenatal and tuberculosis clinics), community-based organizations (CBOs), community health centers, and mobile test sites. The number of HIV tests conducted each year at publicly funded counseling and testing sites has been increasing steadily each year, from 39,298 tests in 1999 to 47,536 tests in 2004 (Table 31). This increase in tests may be due to increases in HIV awareness among community members, increased focus of HIV-STD interactions among clinicians, and Syphilis Elimination Project activities, which include HIV testing among those patients screened in health department, correctional facilities, and outreach programs.

The State of Tennessee offers only confidential testing. Overall, in 2004, tests were provided equally for females and males. Additionally, 46% of those tested were among Black, non-Hispanics and 45% were among White, non-Hispanics. The majority of tests were conducted for individuals in the 20-29 year age group (44%). Metropolitan areas provided the majority of HIV tests in 2004; 37% of the HIV tests were performed in either Shelby or Davidson Counties (Table 31). The demographic characteristics of persons tested have been relatively stable over the past five years.

In terms of percentages of positive HIV tests, men had higher total percentages than women did (1% vs. <1%, respectively). Black, non-Hispanics had higher percentages of positive tests when compared to White, non-Hispanics (1% vs. <1%, respectively), and the largest percentages of positive tests came from people aged 30-39. The highest percentages of positive tests were found in Shelby County, where 2% of total HIV tests performed in 2004 were positive (Table 31).

Table 30: HIV counseling and testing data by demographics and testing region, Tennessee, 2004

	Total Tested	# Positive	% Positive
Sex			
Male	23,898	351	1
Female	23,638	154	<1
Race			
White, non-Hispanic	21,510	138	<1
Black, non-Hispanic	21,946	306	1
Other	4,080	14	<1
Age (years)			
<5	24	0	0
5-12	86	0	0
13-19	9,329	18	<1
20-29	21,115	136	<1
30-39	8,842	180	2
40-49	5,595	127	2
>=50	2,545	44	1
Consortia Region			
Davidson	7,123	72	1
East	2,258	5	<1
Hamilton	2,863	8	<1
Knox	4,810	24	<1
Madison	1,820	10	<1
Mid Cumberland	4,387	17	<1
Shelby	10,398	288	2
South Central	2,875	7	<1
Southeast	1,587	3	<1
Sullivan	623	1	<1
Upper Cumberland	1,591	3	<1
West	5,754	61	1
Total	46,089	499	1

Question 4: What are the Patterns of Service Utilization of HIV-Infected Persons in Tennessee?

Highlights

- Ryan White CARE Act Title II clientele reflected the population in Tennessee affected by the epidemic in 2004. The sociodemographic characteristics of these individuals were similar to HIV/AIDS cases reported to Tennessee HIV/AIDS/STD Surveillance and Data Management Section by gender, race/ethnicity, and age group.
- During 2004, Ryan White CARE Act Title II funds were used primarily to provide case management, medical care, and food bank services to among the 96% of clients who received services out of the 7,403 enrolled in the program.
- Through the Tennessee HIV/AIDS Drug Assistance Program (HDAP) 1,481 persons were enrolled, with 68% being prescribed antiretroviral medications in 2004. The majority of clients who received HDAP supported medications were male, Black, non-Hispanic, and 35-44 years of age.

The following section focuses on information that pertains to Health Resources and Services Administration (HRSA) HIV/AIDS care planning groups. Specifically, this section characterizes service utilization patterns of various subpopulations within Tennessee. The information presented has been provided by HRSA funded programs as well as supplemental studies that have been conducted to examine specific aspects of HIV care in Tennessee.

In 1990, Congress enacted the Ryan White CARE Act to provide funding for states, territories, and eligible metropolitan areas to offer primary care and support services for individuals living with HIV disease who lack health insurance and financial resources for their care. Congress reauthorized the Ryan White CARE Act in 1996 and in 2000 to support Titles I-IV Special Projects of National Significance (SPNS), the

HIV/AIDS Education Training Centers and the Dental Reimbursement Program, all of which are part of the CARE Act. The purpose of Title II funding is to improve the quality, availability, and organization of health care and support services for individuals and families with HIV disease in each state or territory.

In addition, the funding provides access to needed pharmaceuticals through the HIV/AIDS Drug Assistance Program (HDAP). For the purpose of this profile, service utilization patterns and sociodemographic characteristics of persons who received services funded by the State of Tennessee's Ryan White Title II Program, as well as persons who have been reported to the State of Tennessee's HIV/AIDS Surveillance Program, will be described.

Table 31. Demographic characteristics of CARE Act Title II clients compared with characteristics of persons living with HIV/AIDS, Tennessee, 2004

	CARE Act Clients (N= 7,403)	Estimated Number of Persons Living with HIV/AIDS (N= 12,069)
Race/Ethnicity		
White, non-Hispanic	2,915 (39%)	5,108 (42%)
Black, non-Hispanic	4,102 (55%)	6,614 (55%)
Hispanic	85 (1%)	270 (2%)
Asian/Pacific Islander	21 (<1%)	38 (<1%)
American Indian/Alaskan Native	10 (<1%)	9 (<1%)
Unknown/Multiple Race	270 (4%)	28 (<1%)
Sex		
Male	5,204 (70%)	9,046 (75%)
Female	2,179 (29%)	3,023 (25%)
Transgender	20 (<1%)	–
Age (years)		
<13	307 (4%)	81 (<1%)
13-14	51 (<1%)	9 (<1%)
15-24	390 (5%)	572 (5%)
25-34	1,445 (20%)	2,650 (22%)
35-44	2,888 (39%)	4,953 (41%)
45-54	1,757 (24%)	2,872 (24%)
55-64	456 (6%)	765 (6%)
>=65	109 (1%)	168 (1%)

Ryan White CARE Act

In 2004, 7,403 clients were enrolled in the Ryan White Title II program. During the year, the distribution of Title II CARE Act clients by age and race/ethnicity was similar to the distribution of these characteristics among persons known to be living with HIV/AIDS in Tennessee as of year-end, 2004 (Table 31).

Table 32. Ryan White Title II service utilization by service type, Tennessee, 2004

	Clients Receiving Service (No.)	Visits per Client (average)	Total Service Visits	
			No.	%
Case Management	4,084	8.1	33,212	36
Medical	3,855	3.6	13,954	15
Food Bank	1,561	6.7	10,445	11
Transportation	933	6.0	5,583	6
Referral for Health Care	2,254	2.2	4,868	5
Mental Health	790	4.8	3,797	4
HIV Treatment Adherence	1,486	2.5	3,691	4
Nutrition Counseling	1,012	3.4	3,444	4
Early Intervention	1,384	1.9	2,604	3
Education/Risk Reduction	1,128	1.8	2,046	2
Other Support Services	962	1.6	1,575	2
Psychosocial Support	89	16.6	1,479	2
Dental	931	1.4	1,262	1
Home Health Care	27	36.2	978	1
Emergency Financial	418	2.2	908	1
Client Advocacy	275	2.4	664	1
Housing Assistance	172	2.7	458	<1
Other Counseling	213	2.1	442	<1
Referral for Clinical Trials	376	1.0	379	<1
Service Outreach	46	1.6	72	<1
Substance Abuse	33	1.2	39	<1
Buddy Companion Visit	12	2.5	30	<1
Legal Service	21	1.0	21	<1
Rehabilitation Service	10	1.7	17	<1
Permanency Planning	2	1.0	2	<1
Child welfare	1	1.0	1	<1
Total	7,120	12.9	91,971	100

A total of 7,120 (96%) Tennessee Title II enrollees received one or more services during 2004, accounting for 91,971 service visits. The majority of service visits involved

case management (n=33,212), followed by medical care (n=13,954) and food bank/home-delivered meals (n=10,445).

The difference between the number of clients enrolled in the Title II CARE Act program (n = 7,403) and the number who actually received services (n = 7,120) should be explained. Of these 283 clients, some have died, moved to another state, gained insurance coverage, or chose not to cooperate with their treatment plan. As a result, the records for these clients may not be reflective of their current situation.

HIV/AIDS Drug Assistance Program (HDAP)

Since 1987, Congress has appropriated funds to assist states in providing FDA-approved antiretroviral therapies to AIDS patients. With the initial passage of the Ryan White CARE Act in 1990, the assistance programs for antiretroviral therapies were incorporated into Title II and became commonly known as HDAP. HDAP now provides FDA approved HIV-related prescription drugs to under-insured and uninsured individuals living with HIV/AIDS. For many people with HIV, access to HDAP serves as a gateway to a broad array of healthcare and supportive services as well as other sources of coverage including TennCare, Medicare, and private insurance.

In Tennessee, persons enrolled in HDAP have been able to receive the following classes of antiretroviral drugs: nucleoside/nucleotide analogues, non-nucleosides, protease inhibitors, and entry inhibitors. According to the HDAP database, 1,481 clients were enrolled in Tennessee during 2004 (Table 33). Most Tennessee HDAP clients served during this year were male (79%), age 35-44 years (43%), and Black, non-Hispanic (48%) or White, non-Hispanic (46%).

HIV Medical Care in Tennessee

The prioritization and allocation of Ryan White Title II resources requires an understanding of medical care patterns among persons living with HIV/AIDS, as well as those already receiving care through Title II services. Monitoring the proportion of HIV-

infected individuals who receive recommended standards of care may help public health entities to explain observed differences in morbidity and mortality associated with HIV infection. Although the current HIV/AIDS surveillance system in Tennessee does not collect extensive HIV medical care data, this information is collected in the HDAP database for some patients.

Table 33. Characteristics of persons enrolled in the HIV/AIDS Drug Assistance Program (HDAP), Tennessee, 2004

Sex	Number	Percent
Male	1,163	79
Female	312	21
Transgender	3	<1
Other	3	<1
Total	1,481	100
Race/Ethnicity		
White, non-Hispanic	674	46
Black, non-Hispanic	715	48
Hispanic	58	4
Asian	9	1
Pacific Islander	1	<1
Native American	0	-
Other	24	2
Total	1,481	100
Age (yrs)		
<13	4	<1
13-14	0	-
15-24	82	6
25-34	352	24
35-44	640	43
45-54	322	22
>=55	80	5
Unknown	1	<1
Total	1,481	100

Prescription of Antiretroviral Therapy

According to data retrieved from the HIV/AIDS Drug Assistance Program, there were 1,011 persons who were prescribed antiretroviral therapy (ART) or highly active antiretroviral therapy (HAART) by their health care provider in 2004 (Table 35). Patients receiving medications were predominately male (80%), Black, non-Hispanic (58%), and age 35-44 years (44%).

Table 34. HIV+ patients prescribed antiretroviral therapy (ART) and highly active antiretroviral therapy (HAART), by sex, race/ethnicity and age group, Tennessee, 2004

Sex	Number	Percent
Male	813	80
Female	182	18
Transgender	3	<1
Other/Unknown	13	1
Total	1,011	100
Race		
White, non-Hispanic	314	31
Black, non-Hispanic	582	58
Hispanic	55	5
Asian/Pacific Islander	2	<1
Pacific Islander	1	<1
Native American	2	<1
Other/Unknown	55	5
Total	1,011	100
Age (yrs)		
<13	2	<1
13-14	0	-
15-24	36	4
25-34	263	26
35-44	445	44
45-54	196	19
>=55	56	6
Unknown	13	1
Total	1,011	100

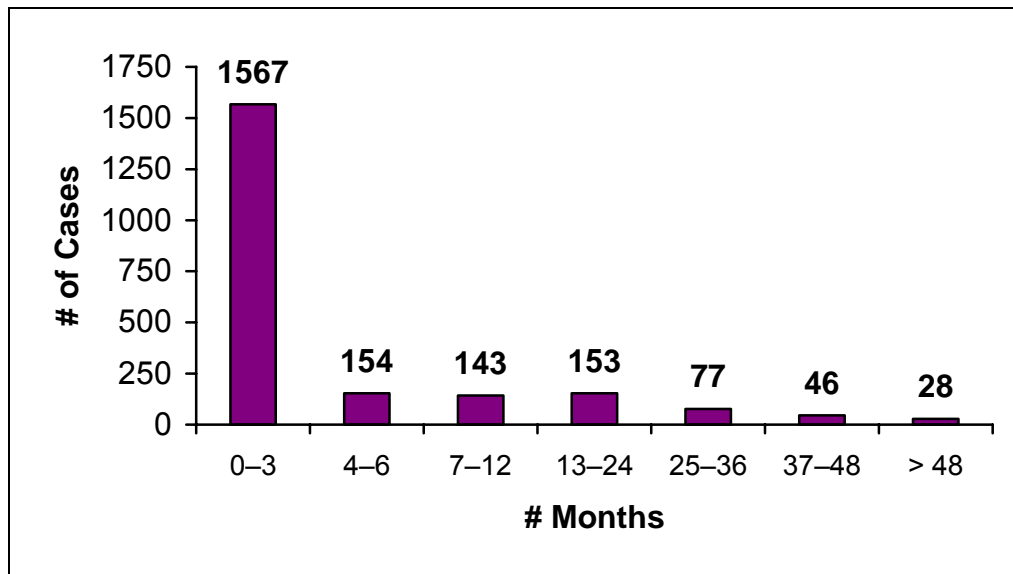
There were 2,837 antiretroviral prescriptions recorded among these patients through HDAP. Table 35 shows the number of prescriptions of each drug broken down by the category that each medication is assigned. According to this table, there were 1,560 (55%) Nucleoside/Nucleotide Analogs (NRTIs), 797 (28%) Protease Inhibitors, 474 (17%) Non-Nucleosides (NNRTIs), and 6 (<1%) Entry Inhibitors prescribed for patients in 2004.

Table 35. Number of prescriptions recorded for antiretroviral drugs by category, Tennessee, 2004

Drug	Category			
	Nucleoside/ Nucleotide Analogs (NRTIs)	Protease Inhibitors (PIs)	Non-Nucleosides (NNRTIs)	Entry Inhibitor
Agenerase		2		
Crixivan		24		
Combivir	411			
Epivir	219			
Emtriva	56			
Epzicom	5			
Fortovase		7		
Fuzeon				6
Invirase		6		
Kaletra		232		
Lexiva		46		
Norvir		151		
Reyataz		145		
Retrovir	38			
Rescriptor			1	
Sustiva			370	
Trizivir	137			
Truvada	44			
Videx EC	143			
Viracept		184		
Viramune			103	
Viread	300			
Zerit	134			
Ziagen	73			
Total:	1,560	797	474	6

HIV Testing Delays

Figure 9. Time between First Positive HIV Test and AIDS Diagnosis, Tennessee, 2000-2004



With the current availability of antiretroviral therapies, which have often been successful in treating HIV-infected persons, it is important that people are tested early for HIV so that they can benefit from these treatment advances. However, a significant number of people do not undergo testing for HIV until they become immunosuppressed and/or symptomatic. A total of 5,208 persons were initially reported to the Tennessee HIV/AIDS Registry between 2000 and 2004 based on a confidential positive HIV test. Of these 2,168 have progressed to AIDS, with 1,567 (72%) being diagnosed within three months of their initial reported positive HIV test. Figure 9 shows the time between a person's first positive confidential test and AIDS diagnosis among patients who initially tested positive for HIV during the period 2000-2004. Even though antiretroviral treatment may delay the onset of AIDS-related symptoms, a sizable proportion among these cases was seen to subsequently progress to AIDS soon following their initial HIV-positive test.

This is suggestive of a significant testing delay, as many of these individuals would have likely benefited from early HIV detection and ensuing initiation of antiretroviral therapy.

This graph should be interpreted cautiously because it is based solely on data from the state registry. A more accurate depiction would necessitate inclusion of only new 2000-2004 HIV-positive cases that transitioned to AIDS, not just those who were reported during this period. For example, a person could have been tested for HIV earlier but anonymously, or an individual could have received prior HIV testing in a non-traditional venue (e.g. home testing kits, health screenings). In these instances, because the actual dates of initial HIV-positive diagnosis are not captured in the registry, the numbers illustrated for this period may tend to be inflated.

Question 5: What are the Characteristics of Persons Who Know They are HIV-Positive but are not Receiving HIV Primary Medical Care in Tennessee?

Efforts to measure unmet need among persons with HIV infection are underway in Tennessee. The Tennessee Department of Public Health HIV/AIDS/STD program has developed a new approach at identifying individuals who know their HIV status but are not receiving primary medical care. This project focuses on enumerating the number of individuals who are reported as HIV-infected, currently living in Tennessee, and are receiving routine medical care, versus those who are not receiving care.

Highlights

- As of 12/31/2004, 54% of persons who are aware of their HIV-infected status in Tennessee had not received CD4 or viral load testing, or received antiretroviral therapy in the previous 12 months.
- Although the 2005 Tennessee Statewide Consolidated HIV/AIDS Needs Assessment results cannot be generalized to reflect care and support service requirements for all HIV-infected residents, those most frequently noted as lacking include: dental care, housing assistance, transportation, and nutritional services.

Measuring Unmet Need

Tennessee's State Reporting laws require that laboratories report all tests indicative of HIV infection performed on persons residing in Tennessee (i.e., ordered by facilities operating in Tennessee). Once the tests have been reported to the HIV/AIDS Surveillance Program, the results can be linked to records maintained in the HIV/AIDS case registry, which defines the population of persons living with HIV in Tennessee. Consequently, for a specified time period, each HIV-infected person can be characterized as "in care" or "not in care" by either the presence or absence of a laboratory test (e.g.,

CD4 or viral load), or received antiretroviral therapy during that time period. This method, however, assumes that laboratory reporting is complete. Reporting is complete only if all laboratories that perform tests for HIV care facilities in Tennessee report their results to the HIV/AIDS Surveillance Program, which is currently being evaluated.

A preliminary analysis of the laboratory information was conducted to determine which proportion of persons living with HIV/AIDS during 2004 accessed the health care system to receive care for their infection. This analysis sought to detect additional issues or biases that may affect the analysis of unmet need. Subsequent analyses will identify factors associated with accessing care and will investigate issues such as patterns of care utilization (e.g., continuity of care within the same facility, changing facilities of care) and remaining in care. The resulting analysis then generated estimates of unmet need based on a method developed for HRSA by the University of California, San Francisco. Results from this analysis will be used to improve future analyses, and will provide information for community-planning groups and service providers about the Unmet Needs of HIV-infected patients in Tennessee.

According to current HRSA Guidelines, HIV unmet need is defined as “an individual with HIV or AIDS is considered to have an unmet need for care when there is no evidence in the past 12 months that s/he received either viral load testing, CD4 count testing, or antiretroviral therapy”⁵ (Kahn et al, 2003). Calculation of HIV unmet need was included in the 2000 Amendments to the Ryan White CARE Act, which require each Title I and II Program to:

- Determine the size and demographics of the population of individuals with HIV infection
- Determine the needs of such populations, with particular attention to both people with HIV disease who know their HIV status and are not receiving “HIV-related services” and “disparities in access and services among affected subpopulations and historically underserved communities”

5. Kahn JG, Janney J, Franks PE. A practical guide to measuring unmet need for HIV-related primary medical care: Using the Unmet Need Framework. Unpublished report, University of California at San Francisco; 2003.

For this analysis, surveillance staff used the HIV/AIDS Reporting System (HARS), the Ryan White CAREWare reporting system, and HIV Drug Assistance Program Database (HDAP) to generate a master list of known Tennessee residents living with HIV/AIDS. Using information from all three databases, evidence of one of the following indicators was identified:

- Viral Load Testing
- CD4 Count Testing
- Antiretroviral Therapy Use

As this is the second year conducting these analyses, there are several limitations that should be noted when attempting to measure HIV unmet need. First, these analyses only included patients reported within the Tennessee HIV/AIDS Reporting System (HARS) as of 12/31/2004. Second, TennCare patient data were not available for inclusion in this study; thus, these results do not include patients who sought treatment from TennCare providers. Additionally, data from private providers who treat HIV patients (but are not affiliated with a Tennessee AIDS Centers of Excellence) are not normally available. According to state law, providers are obligated to report positive HIV test results to local health departments, but there is always a possibility that these results are reported well after HIV/AIDS diagnoses, or not at all. Due to these limitations, extreme caution should be used in evaluating these statistics. Anecdotal evidence suggests that HIV/AIDS providers are doing an excellent job at providing care to those infected with HIV. Nonetheless, with a lack of supportive data for 2004 this statement cannot be substantiated.

Results of Unmet Need Analysis

As noted in the introduction, approximately 54% of all Tennessee residents who were aware of their serostatus had unmet need in 2004 (as defined previously). From Table 37 below, there were 12,632 HIV/AIDS infected patients included in this study. Of this population, 5,859 (46%) were found to have utilized one or more of the three indicators of met need sometime in 2004, while the remaining 6,773 (54%) were identified as having unmet need. The majority of cases with met need were patients with

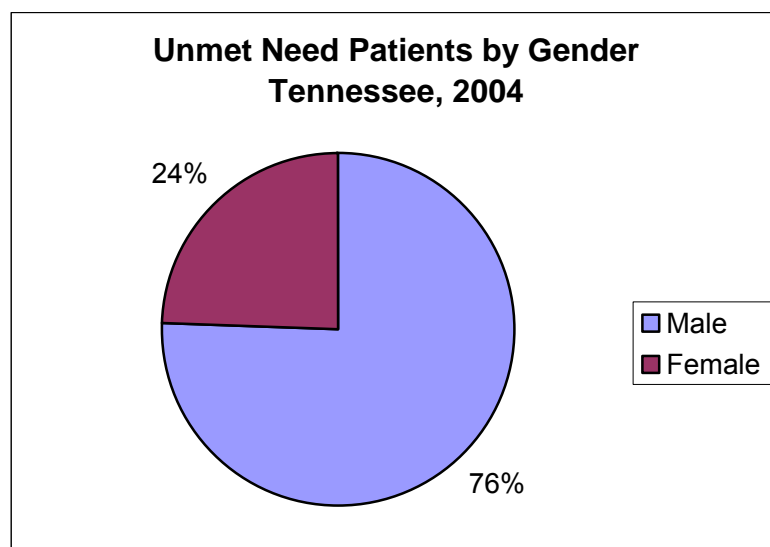
AIDS (60%), which makes sense as these patients would be more likely to seek regular medical care. Of the total who had unmet need, the proportion included more patients not afflicted with AIDS-related syndromes (36% for AIDS, 64% for HIV).

Table 36: Met Need and Unmet Need patients by diagnosis, Tennessee 2004

Need and Diagnostic Status		#	%
Unmet Need	AIDS	2,462	36
	HIV	4,331	64
Unmet Need Total		6,773	100
Met Need	AIDS	3,523	60
	HIV	2,336	40
Met Need Total		5,859	100
Grand Total		12,632	

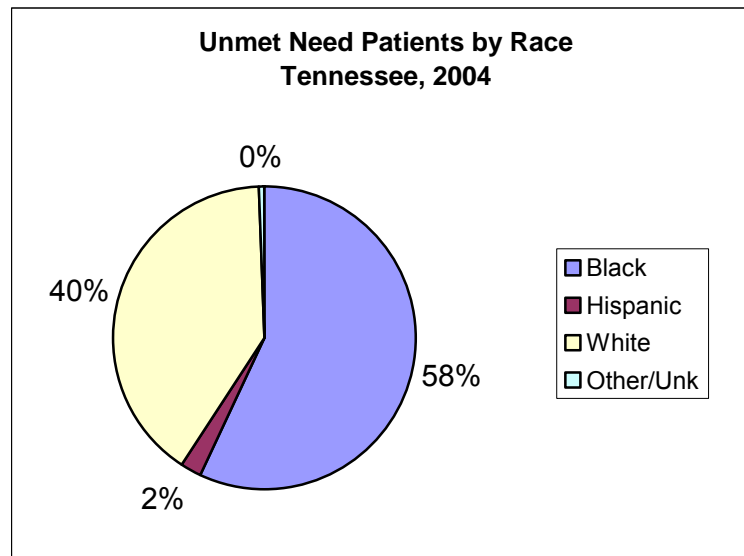
Evaluating unmet need patients by gender, race, age, and risk category yields results that are similar to those of the HIV population as a whole throughout Tennessee. Males comprised approximately 76% of those with unmet need, while females accounted for 24% (Figure 10).

Figure 10: Unmet Need Patients by Gender, Tennessee, 2004



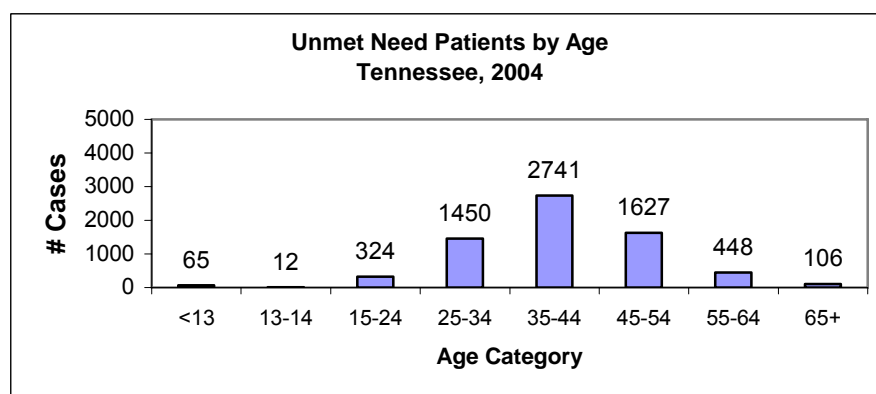
Black, non-Hispanics comprised the largest proportion of those patients with unmet need (58%), followed by White, non-Hispanics who accounted for 40% of this total. Hispanics and other races comprised only 2% of the total unmet need population, comparable to their representation among statewide HIV/AIDS cases (Figure 11).

Figure 11: Unmet Needs Patients by Race, Tennessee, 2004



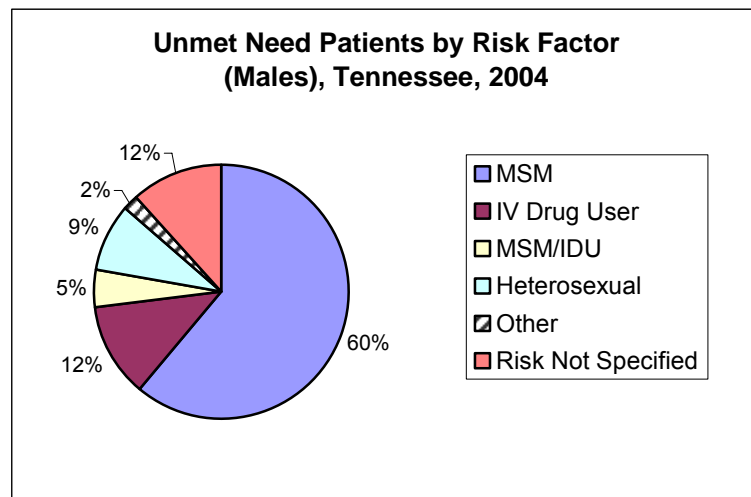
Unmet need patients were primarily comprised of those people over 25 years of age (Figure 12). The majority of patients were 35-44 years old as of 12/31/2004 (40%), followed by 45-54 year olds (24%) and 25-34 year olds (21%). Children under the age of 15 years represented 1% of these cases.

Figure 12: Unmet Need Patients by Age, Tennessee, 2004



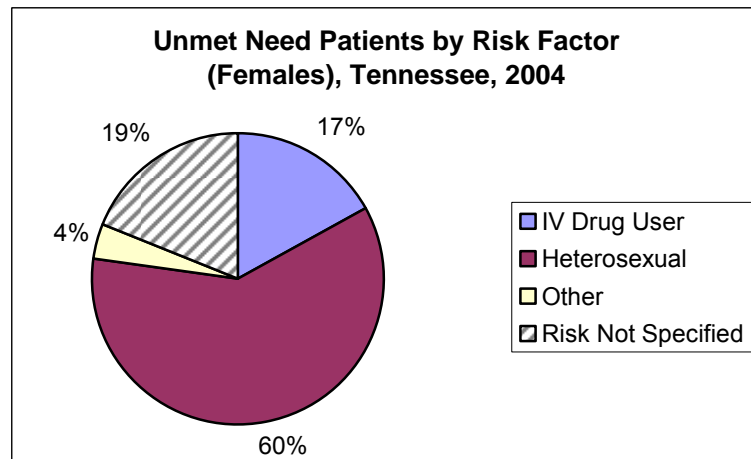
Among male patients with unmet need, MSM was the most commonly reported risk category (60%), followed by IV drug use (12%), heterosexual contact (9%), and MSM/IDU (5%). Twelve percent (12%) of males had risks that were not specified, while two percent (2%) of males had other risks, which include transmission via transplant operations and transfusions (Figure 13).

Figure 13: Male Unmet Need Patients by Risk Factor, Tennessee, 2004



Female patients with unmet need were predominately infected through heterosexual contact (60%). IV drug use accounted for 17% of female patients, and 19% had non-specified risks (Figure 14).

Figure 14: Female Unmet Need Patients by Risk Factor, Tennessee, 2004



Consolidated HIV/AIDS Needs Assessment Survey

Design

This survey was developed to meet current and future grant requirements specified by the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). Additionally, this survey was developed to combine disparate needs assessments used throughout the state into a single, statistically comparable tool. Based on meetings attended by members of consortia groups, community planning groups, and health department staff, a list of 24 core questions was developed that satisfied data needs for both prevention and care planning purposes at the state level. These questions included common elements, such as core demographic data (gender, age, race, etc.) as well as questions relating to the availability of HIV prevention and care services offered. Questionnaires were administered to a cross-section of Tennessee residents chosen anonymously. Analyses were performed at the statewide and Consortia/CPG Region levels in order to provide a more detailed examination of prevention and care needs across the state.

Data Collection

Epidemiologists from the Tennessee Department of Health's HIV/AIDS Surveillance & Data Management Program, with guidance from the HIV Prevention and Ryan White Programs, developed this survey instrument. Staff from various regional consortia/CPG, centers of excellence (COE), and county health departments during the period of 10/4/2005 – 11/18/2005 administered this survey. The questionnaire contains multiple-choice questions, with areas for additional written input that capture important demographic data, as well as information used to measure the availability and satisfaction of prevention and care services.

Data Analysis

Univariate analysis was used to calculate frequency distributions for survey questions. In this preliminary review, analyses were focused on the entire respondent population regardless of HIV status. The exception is for Questions 13-17, which

involve care and support service issues targeted specifically to HIV-positive respondents only. Responses to each question are displayed as percentages at the state level.

Results

A total of 1,286 surveys were returned for analysis. Preliminary review of care and support service utilization among HIV-positive respondents (N=349) revealed that 26% lack access to dental care. Other care and support services identified as deficient within this population included need for emergency housing assistance (9%), transportation (7%), and nutritional services (7%). In a future report (to be released mid-2006), a more detailed and stratified analysis will be conducted to further elucidate responses from various demographic groups. Analyses of responses by HIV status, geographic location, and race/ethnicity, for example, should prove helpful in planning and allocating support and care services throughout Tennessee.

Limitations

Several limitations must be kept in mind when viewing these data. First and foremost, because this survey was not conducted using a random sample methodology, the results contained are not representative of the population in general. Thus, care should be taken in extrapolating these results to any group other than the original survey respondents (e.g. White female respondent answers within the survey may or may not be similar to those of White females who did not participate in the survey). Second, a large number of surveys had missing responses to one or more questions. In some cases, these omissions were quite extensive, which ultimately may skew how these results may be interpreted (e.g., respondents in correctional facilities may tend to abstain from answering questions concerning alcohol/drug use). In general, caution should be used when evaluating percentages that were derived from small number counts. Finally, this analysis is comprised of all respondents, regardless of race, age, gender, or HIV status. When reviewing the responses bear in mind that if the data were stratified differently, such as specifying HIV-infected individuals only, the survey responses would possibly be quite different. Lastly, questionnaires were not always completed in their entirety. As a consequence, result tabulations for individual questions may not sum to 100%.

HIV Prevention and Care Needs Assessment
Survey Results
(N=1,286)

Please put a check in the box next to the answer that best describes you.

1. You are...

Male (50%)
Female (49%)
Transgender (1%)

2. You have sex with... (Check all that apply)

Male (63%)
Female (35%)
Transgender (1%)

3. Your age is...

Under 13 (<1%)	35-44 (28%)
13-14 (1%)	45-54 (17%)
15-24 (22%)	55-64 (7%)
25-34 (23%)	65 and over (1%)

4. Your race is...

Black/African American (34%)	American Indian/ Alaskan Native (<1%)
White/Caucasian (61%)	Native Hawaiian/ Pacific Islander (<1%)
Asian (1%)	
Multiple Race (1%)	
Other (1%)	

5. Your ethnicity is...

Hispanic/Latino(a) (2%)
Non-Hispanic/Non-Latino(a) (79%)

6. What is the highest level of education you have completed?

8th grade or less (3%)	Bachelor's degree (16%)
Some high school (14%)	Master's Degree (6%)
High school diploma/GED (27%)	Doctoral Degree (1%)
Some college/Associates (29%)	Choose Not to Answer (1%)

7. Please indicate where you are completing this survey.

Care Facilities (22%)	General Business (for example, restaurant, barbershop, nail salon, grocery store, etc.) (6%)
Street Outreach (18%)	Primary/Secondary School (2%)
Bar/Club (2%)	Correctional Facility (4%)
Place of Worship (5%)	Other (5%)
Homeless Shelter (1%)	
A&D Facility (7%)	
Trade School/College/University (7%)	

8. What do you consider your primary language?

English (98%)
Spanish (1%)
Other (1%)

9. What is your current living situation?

Own/Rent (66%)	Live with Family (3%)
Shelter/Temporary Housing (17%)	Correctional Facility (<1%)
Homeless (2%)	Full-Time Student (4%)
Nursing Facility (4%)	Other (2%)

10. Your current job situation is...

Full-time employed (30 or more hours per week) (40%)
Part-time employed (less than 30 hours per week) (14%)
Unemployed (30%)
Retired (3%)
Other (11%)

11. Have you been tested for HIV in the past 12 months?

Yes (45%)
No (51%)
Unknown (2%)

12. Your HIV status is...

HIV-negative (*Skip to Question 18*) (49%)
HIV-positive (27%)
Unknown (*Skip to Question 18*) (19%)

[Questions 13 – 17 are targeted at respondents who identify themselves as HIV-positive]
(N=349)

13. You most likely contracted HIV by...

Sex with a man (68%)	Mother to child (1%)
Sex with a woman (12%)	Blood transfusion/Hemophilia (2%)
Sex with a transgender (1%)	Other (1%)
Sharing of needles (8%)	Unknown (4%)
Occupational exposure (1%)	

14. For the following care and support services, please indicate whether you receive the service, need but cannot get the service, or don't need the service.

	Receive this Service	Need but cannot get	Don't Need
a. Medical visits	(73%)	(2%)	(9%)
b. Medications	(69%)	(3%)	(11%)
c. Dental services	(42%)	(26%)	(11%)
d. Case management	(68%)	(4%)	(11%)
e. Transportation	(38%)	(7%)	(35%)
f. Nutritional services	(41%)	(7%)	(30%)
g. Emergency housing assistance	(18%)	(9%)	(44%)

15. Have you been told by your healthcare provider that you have AIDS?

Yes (61%)
No (35%)

16. Do you take any HIV/AIDS Medications?

Yes (81%)
No (17%)

17. You pay for your HIV/AIDS related medical needs with...(Check all that apply)

TennCare (48%)	Self Pay (9%)
Medicare (20%)	Other (5%)
Private Insurance (14%)	Do Not Receive Care (3%)
Veterans Administration (VA) (3%)	Ryan White/IAP/HDAP (29%)
Champus/Tricare (<1%)	

18. Within the past twelve months, have you been diagnosed with any of the following?

	Yes	No	Do Not Know
a. Hepatitis A or B	(2%)	(89%)	(2%)
b. Hepatitis C	(4%)	(88%)	(2%)
c. Syphilis	(1%)	(90%)	(2%)
d. Genital Herpes	(1%)	(90%)	(2%)
e. Gonorrhea	(1%)	(89%)	(2%)
f. Chlamydia	(2%)	(89%)	(2%)
g. Genital Warts	(2%)	(89%)	(2%)
h. Yeast Infection	(7%)	(84%)	(2%)
i. Other	(3%)	(62%)	(1%)

19. Within the past twelve months, you have used the following substances...

	None	A couple of times during the past 12 months	Once a month	Once a week or more	Choose not to answer
a. Alcohol	(33%)	(20%)	(11%)	(28%)	(2%)
b. Marijuana (Weed)	(66%)	(10%)	(3%)	(11%)	(2%)
c. Crack/Cocaine	(76%)	(5%)	(1%)	(6%)	(2%)
d. Crystal Meth or Methamphetamines	(82%)	(3%)	(1%)	(3%)	(1%)
e. Ecstasy (X)	(83%)	(2%)	(1%)	(1%)	(1%)
f. Heroin	(85%)	(1%)	(<1%)	(1%)	(1%)
g. Other	(58%)	(1%)	(<1%)	(3%)	(1%)

20. You believe that your sexual behavior...

- Has a high risk of getting/giving disease to your sexual partner(s) (6%)
- Has a moderate risk of getting/giving disease to your sexual partner(s) (8%)
- Has a low risk of getting/giving disease to your sexual partner(s) (21%)
- Has no risk of getting/giving disease to your sexual partner(s) (30%)
- Not sexually active (26%)

21. Indicate how much you agree with the following statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. I am responsible for informing my partner(s) of my HIV status	(7%)	(1%)	(3%)	(13%)	(67%)
b. There is no risk of having unprotected sex with an HIV+ person	(68%)	(10%)	(3%)	(4%)	(7%)
c. It is my partner's responsibility to protect themselves during sex	(32%)	(14%)	(12%)	(13%)	(18%)
d. Condoms ruin sex	(38%)	(23%)	(16%)	(7%)	(5%)
e. Using a condom is not a habit for me	(31%)	(16%)	(14%)	(15%)	(10%)
f. I am usually high and/or under the influence of alcohol/drugs when I have sex	(52%)	(16%)	(11%)	(5%)	(3%)
g. My partner insists that we do not use a condom	(37%)	(18%)	(19%)	(7%)	(5%)
h. I am too embarrassed to suggest the use of a condom with my partner	(54%)	(17%)	(11%)	(3%)	(2%)

22. For the following prevention services, please indicate whether you receive the service, need but cannot get the service, or don't need the service.

	Receive this Service	Need but cannot get	Don't Need
a. HIV testing	(45%)	(4%)	(40%)
b. Individual level counseling concerning safe sex, testing, prevention	(30%)	(5%)	(53%)
c. Group level education concerning safe sex, testing, prevention	(27%)	(5%)	(56%)
d. HIV hotline	(16%)	(6%)	(66%)
e. Businesses that provide free condoms	(31%)	(7%)	(49%)
f. Out reach workers: community people that provide education and information on HIV and places that provide services such as testing	(30%)	(6%)	(51%)
g. Community meetings that allow me to have input in what HIV prevention programs are provided in my area	(23%)	(9%)	(52%)

**23. I do not receive HIV prevention services and/or care/support services because...
(Check all that apply)**

I do not have transportation (7%)

The organization that I tried to get
services from was not helpful (2%)

I am unsure what organizations
provide the services that I need (10%)

I felt that the people at the organization
were judging me (2%)

Programs that I need do not fit into
my schedule (5%)

I am unsure where to start to get
information/services (13%)

I do not have childcare (3%)

Someone may recognize me (4%)

**24. Indicate whether you have received information about HIV education, community
announcements, HIV service providers, etc. from the following sources in the
past 12 months.**

Doctor/Medical provider (42%)

Television/Radio (33%)

Billboards (13%)

Newsprint: local paper, flyers,
etc (24%)

Speaking with experts in
workshops/group settings (22%)

Speaking with people like me in
peer groups (21%)

☐ Internet (16%)

☐ Friends (25%)

☐ Other (12%)

APPENDIX A: PROFILE DATA SOURCES

1. Core HIV/AIDS Surveillance

AIDS Surveillance

Overview: AIDS is a reportable condition in all U.S. states and territories. Since 1993, all states and territories base their reporting practices upon the 1993 CDC case definition for AIDS surveillance. The AIDS Surveillance system was established to monitor incidence of the disease and the demographic profile of AIDS cases; describe the modes of HIV transmission among persons diagnosed with AIDS; guide the development and implementation of public health intervention and prevention programs; and to assist in the evaluation of the efficacy of public health interventions. AIDS surveillance data are also used to allocate resources for Titles I and II of the Ryan White CARE Act.

State and local health departments actively solicit disease reports from health care providers and laboratories. Standardized case report forms are used; these forms are used to collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status, and referrals for treatment or services.

Population: All persons who meet the 1993 CDC AIDS surveillance case definition.

Strengths: This is the only source of AIDS information that is available in all areas (states). The data reflect the impact of AIDS on communities and trends of the epidemic within communities. AIDS Surveillance has been determined to be >85% complete. The data include all demographic groups (age, race/ethnicity, sex).

Limitations: Due to the prolonged and variable period from infection to the development of AIDS, trends in AIDS surveillance do not represent recent HIV infections. Asymptomatic HIV-infected persons are also not represented by AIDS case data. In addition, incomplete HIV or CD4+ t-cell testing may interfere with the completeness of

reporting. Further, the widespread use of HAART complicates the interpretation of AIDS case surveillance data and estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt progression of HIV infection to AIDS. AIDS cases represent late stage HIV infections.

HIV Surveillance

Overview: Since the human immunodeficiency virus was identified and a test for HIV was licensed, CDC and other professional organizations have recommended reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities. As part of ongoing, active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, and establish liaisons with laboratories that test for HIV infection. Moreover, HIV/AIDS surveillance programs routinely evaluate the completeness of HIV reporting and conduct follow-up on HIV cases that are of epidemiologic importance.

Population: All persons who test positive for the Human Immunodeficiency Virus (HIV).

Strengths: HIV surveillance data represent more recent infections, compared with AIDS surveillance data. Based upon previous evaluations, HIV infection reporting in Tennessee is estimated to be >95% complete for persons who have tested positive for HIV. Consequently, HIV surveillance provides a minimum estimate of the number of persons known to be HIV-infected and reported to the health department, identifies emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, and women) that may not be evident from AIDS surveillance. Additionally, HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services, and can be used to anticipate unmet needs for HIV care.

Limitations: HIV surveillance data may underestimate the level of recently infected persons because some infected persons either do not know they are infected or have not sought testing. Persons who have tested positive in an anonymous test site and have not sought medical care, where they would be confidentially tested, are not included in HIV surveillance statistics. HIV surveillance data represent infections in jurisdictions where reporting laws for HIV are in place. HIV reporting laws vary by jurisdiction; therefore, consultation with local surveillance staff is advised on how to interpret local HIV surveillance data. Furthermore, reporting of behavioral risk information may not be complete.

Enhanced Perinatal Surveillance

Overview: Perinatal HIV/AIDS surveillance is the ongoing and systematic collection of information on HIV-infected pregnant mothers, and perinatally exposed and HIV-infected children. Extensive medical record abstractions are conducted for all HIV-exposed children and their mothers, and the children are followed up until their infection status is determined. These data address the prevention of perinatal transmission, including prenatal care, HIV counseling and testing during pregnancy, and use of zidovudine or other antiretrovirals among pregnant mothers and neonates. The data also address questions regarding treatment issues for women infected with HIV and their children.

Population: All HIV-exposed children and their mothers.

Strengths: Enhanced perinatal surveillance data provides perinatal-specific information that can be used to examine patterns in HIV testing and in ZDV use in clinical practice, as well as to identify barriers to the implementation of Public Health Services guidelines. Perinatal surveillance data may also be used to help ascertain mother-infant pairs by matching data in the HIV/AIDS registry to the state birth registry each year.

Limitations: Perinatal data may underestimate the number of mother-infant pairs, because some pregnant women may not know they are HIV infected and others may not

have been tested for HIV. Perinatal data includes only those women who have had a positive confidential HIV test. HIV-exposed infants must be followed until sufficient laboratory information is available, so infants who are lost to follow-up cannot be classified as infected or not infected.

2. Behavioral Surveys

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: The BRFSS is a state-based random digit-dialed telephone survey of adults that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. Each month, a sample of households is contacted and one person in the household who is 18 years or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents to the BRFSS questionnaire are asked a variety of questions about their personal health behaviors and health experiences. A sexual behavior module was added to this survey in 1994, 1995, 1996, 1998 and 2000. In this module, adults (ages 18-49) were asked about their number of sexual partners, condom use, and treatment for STDs.

Population: All non-institutionalized adults, 18 years and older that reside in a household with a telephone.

Strengths: Data from the BRFSS survey are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state. Information collected from the BRFSS survey may be useful for planning community-wide education programs.

Limitations: BRFSS data are self-reported, thus the information may be subject to recall bias. BRFSS respondents are contacted by telephone, thus the data are not representative of households that do not have telephones. In addition, BRFSS data are representative of the general non-institutionalized adult population in an area, not just persons at highest

risk for HIV/AIDS. The extent of HIV behavioral risk information collected by the BRFSS questionnaire is limited and inferences can only be made at the state level.

Youth Risk Behavior Survey (YRBS)

Overview: The YRBS was established to monitor six priority high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and young adults in the United States. The YRBS is a self-administered questionnaire given every two years to a representative sample of 9th through 12th grade students at the state and local level. In Tennessee, the survey is administered at the state level within public schools. The YRBS collects information on six categories of behaviors, of which sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases (STDs), including HIV, is one. Questions are also asked about exposure to HIV prevention education materials, sexual activity (age of debut, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and pregnancy history. YRBS uses a standardized questionnaire so that comparisons can be made across participating jurisdictions. Jurisdictions may also add questions of local interest.

Population: YRBS surveys a representative sample of 9th through 12th grade students at the state and local level.

Strengths: The YRBS questionnaire is administered to students anonymously during school. Repeated attempts are made to contact students who are not in attendance. Inferences from YRBS estimates can be drawn about behaviors and attitudes of adolescents in school, which makes the information useful for developing community-wide prevention programs aimed at younger persons. YRBS uses a standardized questionnaire so that comparisons can be made across participating jurisdictions. Jurisdictions have the option to ask specific questions to meet their needs.

Limitations: The YRBS project relies upon self-reported information; therefore, reporting of sensitive behavioral information may not be accurate (under- or over-reporting may occur). Also, since the YRBS questionnaire is administered in school, the

data are only representative of children who are enrolled in school and cannot be generalized to all youth. For example, students at highest risk, who may be more likely to be absent from school or to drop out of school, may be underrepresented in this survey, especially among older grade levels. The questionnaire does not ask about homosexual or bisexual behavior.

3. STD Surveillance

STD Case Reporting

Overview: The Tennessee Office of Public Health STD Control Program conducts statewide surveillance to determine sexually transmitted disease (STD) incidence and to monitor trends. It also conducts partner counseling and makes referrals for examination and treatment in order to reduce the spread of STDs. In Tennessee, chancroid, chlamydia, gonorrhea, lymphogranuloma venereum, and syphilis are reportable STDs.

Population: All persons who are diagnosed with an infection that meets the CDC surveillance case definition for the infection and are reported to local health department.

Strengths: STD surveillance data can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of or changes in a specific behavior (e.g., rectal gonorrhea). STD data are widely available at the state and local level. Because of shorter incubation time periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (i.e., ulcerative STDs) can facilitate transmission and/or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms, such as unprotected sex.

Limitations: STDs are reportable, but requirements for reporting vary across states. Reporting of STDs from private sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk.

4. HIV Counseling and Testing Data

Counseling and Testing System (CTS)

Overview: The Tennessee Office of Public Health provides funds for the HIV CTS in 141 different sites across Tennessee. These sites include CBOs, drug treatment centers, and STD, prenatal, family planning and tuberculosis clinics. The CTS collects information on counseling and testing services delivered, as well as the characteristics of clients receiving the services. The characteristics include demographics, insurance, risk information, and testing information (data, testing history, test result). However, no personal identifying information is collected. All sites offer only confidential testing options.

Population: All clients who receive confidential HIV testing services at a counseling and testing site funded through a CDC cooperative agreement

Strengths: CTS provides standardized data on clients who are tested for HIV, which is available at the local level. It may offer insights into HIV infection rates in an area's high-risk population. CTS testing data may highlight the impact of prevention programs upon populations being targeted.

Limitations: CTS collects test-based, rather than person-based data. Information is collected only from persons who seek counseling and testing services or agree to be tested after consultation with a counselor at a testing site. Therefore, estimation of HIV statewide seroprevalence is not possible with CTS data because the clients self-select for testing. However, in certain sites where testing is universal, cases that are HIV-positive may reflect the prevalence in that population. Because a person can repeatedly seek testing, it is not possible to distinguish individuals who have been tested multiple times; however a 'previous HIV test' variable is available on the client abstract form to quantify prior testing. Since the CTS system gathers data on HIV testing or program activities, changes in testing patterns may reflect changing program priorities rather than testing patterns of individuals.

5. Vital Statistics Data

Birth Data

Overview: The National Center for Health Statistics (NCHS) receives information on births and deaths in the U.S. through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. States use a standard form (U.S. Standard Certificate of Live Birth) to collect birth data and report this information annually to NCHS. The birth certificate form collects newborn, maternal, and paternal demographics; insurance; prenatal care; prenatal risk factors; maternal morbidity; mode of delivery; pregnancy history; and clinical characteristics of the newborn.

Population: All live births occurring within Tennessee.

Strengths: Vital records capture all births that occurred within an area. Reporting is approximately 100% complete. Therefore, inferences can be made concerning the population of live births in a service area. The revised birth certificate collects additional information on maternal insurance status, smoking, and morbidity that may be useful for targeting prevention resources.

Limitations: Birth certificate data are often not complete for data that is obtained from patient medical records (i.e., smoking history, morbidity).

Death Data

Overview: NCHS receives information on births and deaths through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. A standard certificate of death is used to record death information on each decedent. Death certificates capture decedent demographics, underlying cause of death (using an ICD-10 code), and contributions of selected factors to the death (i.e., smoking, accident, or injury).

Population: All deaths occurring within Tennessee.

Strengths: Reporting of deaths in Tennessee is universal and 100% complete. The data are widely available and can be used to determine the impact of deaths related to HIV infection in a service area. Standardized procedures are used throughout the nation to collect death certificate data.

Limitations: Deaths resulting from, or whose underlying cause was, HIV infection may be under-reported on a death certificate. Clinical information related to HIV or AIDS may be missing. Death records are less timely than AIDS case reports.

6. Population Data

U.S. Bureau of the Census (Census Bureau)

Overview: The Census Bureau collects and provides timely information about the people and economy of the U.S. The Census Bureau's website (<http://www.census.gov>) includes data on demographic characteristics (e.g., age, race, Hispanic ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the percentage of persons living at or below the poverty level. Tables and maps of census data are available for all geographic areas to the block level. Summaries of the most requested information for states and counties are provided, as well as analytical reports on population change, race, age, family structure, and apportionment.

Population: U.S. population

Strengths: A wide range of online statistical data on the U.S. population is available in different formats (e.g., tables, maps). State- and county-specific data are easily accessible. Links to other census information websites are provided.

Limitations: Some files may take longer to download.

Health Information Tennessee

Overview: This website is administered by the State of Tennessee's Office of Health Statistics. The website includes current population estimates and projections; economic, income and poverty status information; demographic profiles and rankings; and census geography. Information is available for the state, counties, cities, and metropolitan areas. County population trends are also provided. Links to state census data center local affiliates and to other census information websites are included as well.

Population: Tennessee population

Strengths: A wide range of online statistical data on the Tennessee population is available in different formats (e.g., tables, maps). Links to state census data center local affiliates and to other census information websites are provided.

Limitations: Some files may take longer to download.

9. Ryan White CARE Act Data

Title I and II Statewide HIV/AIDS Needs Report

Overview: Every two years, Ryan White Title I and Title II programs administer a detailed survey to persons living with HIV/AIDS in Tennessee. The purposes of the survey are to gain a greater understanding of the current level of HIV/AIDS service needs, and to provide insight into consumers' perceptions of the availability and quality of HIV/AIDS services throughout the state. Representatives and consumers from Titles I and II jointly developed the methodology and statewide needs assessment instrument. The 2000-2001 survey included a variety of demographic questions (residence, age, race, gender, income levels and sources, and type of health insurance coverage), as well as questions about HIV-related primary care, illness severity, and individual experiences with taking combination therapy medications. Respondents were also asked specific questions about housing, transportation, childcare, drug/alcohol abuse, and needs and opinions regarding various medical and social services. Each region in the state received

a predetermined number of surveys according to the target response goal (a minimum of 10% of persons known to be living with HIV/AIDS in a given region).

Population: Persons living with HIV/AIDS who agreed to complete the Needs Assessment survey. The sample population was weighted heavily toward individuals who were currently in care, since potential respondents were encountered in primary care clinics, social service agencies, community health centers, TennCare enrollment centers, substance abuse or mental health treatment facilities, homeless or transitional shelters, and local jails. The participants primarily accessed services through the Ryan White-funded service delivery system, although some respondents sought services at Veteran's Administration hospitals only, private clinics, or other private providers.

Strengths: The Needs Assessment provides a valuable tool for understanding consumers' perceptions of care in Tennessee. The survey instrument is flexible and can be modified to accommodate new questions as services and care recommendations change.

Limitations: The survey was administered only to persons who visited one of the above mentioned care sites during the eight week period in which the survey was administered. Respondents also had to be willing to participate in the survey process. Persons who were not in care during that time period, not in care at all, or who were unwilling/unable to complete the questionnaire were not surveyed. Thus, the survey provides a measure of the needs of persons who were receiving some type of care, but does not adequately address the needs of those who were not seeking care at all. Since the survey also deals with perceptions of care, many of the responses are qualitative in nature and cannot be generalized to the entire statewide population.

Ryan White Title I CAREWare

Overview: Since 1993, the HIV/AIDS Program of the Tennessee Office of Public Health has collected data on persons served through Tennessee Ryan White Title I funding. Until 1999, data for Consortia-funded services was collected through the DOS-based ToolBox data collection system provided by the HIV/AIDS Bureau (HAB) of the Health

Resources and Services Administration (HRSA). This data collection system was not designed to capture service information for persons that received pharmaceuticals through the state-administered HIV/AIDS Drug Assistance Program (HDAP). As such, in 1996, the HIV/AIDS Program entered into a contract with a local computer programmer to design and implement a comparable data system for persons receiving funds through the HDAP. In late 1999, utilization of the ToolBox data collection system became obsolete due to “Y2K” non-compliance. The HDAP data collection system was then expanded into a more comprehensive data base that was named Tennessee CAREWare.

This database includes key information on all persons receiving assistance through any of the Ryan White Title II funded programs, as well as through State Formula HOPWA funds. Such programs include: Health Insurance Continuation, Home Based Care, Consortia-funded Services (e.g., case management, transportation and medication assistance, child care, mental health therapy counseling); pharmaceuticals provided through the HDAP; State Direct Services (legal services, three primary care contracts and a co-payment and deductible assistance program); and limited emergency rent, mortgage and utility payments. Information collected from service providers throughout the state includes basic demographic and risk information on each of the clients, eligibility verification data (current address, current income, HIV/AIDS diagnosis, Tennessee TennCare number), the type of services received, the date and quantity of services received, the cost of these services, and other pertinent information (history of substance abuse or mental health treatment, veteran status and, for women, current pregnancy status). The data collected are used by the HIV/AIDS Program staff to perform monthly service delivery and fiscal monitoring activities, conduct an annual disparity analysis, track regional utilization trends for quality assurance purposes, and to meet the HAB/HRSA requirements set forth in the Annual Administrative Report and in the new CADR. It is also the expectation of the HIV/AIDS Program that providers utilize this data internally to consistently assess and re-assess their agency’s performance.

Population: All HIV-infected persons receiving Services funded by Ryan White Title II. In order to be eligible for Ryan White Title II services a person must be living with

HIV/AIDS, be a resident of the State of Tennessee, and have an income that is equal to or less than 200% of the current year's FPL. The only exception to this is the Health Insurance Continuation Program, where financial eligibility may be as high as 300% of the FPL.

Strengths: CAREWare is a comprehensive database that includes key fields of information on all persons receiving Ryan White Title II services. The CAREWare database is an important tool for monitoring which Ryan White resources are being utilized, how often and by whom. CAREWare is now the model data collection system provided free of charge to grantees from the HIV/AIDS Bureau at HRSA. It has been modified specifically for the HIV/AIDS Program. Tennessee CAREWare also provides opportunities to review client co-morbidity information and to track the changing needs of the client population from year to year. The program is able to “unduplicate” clients within a particular service or service area, and can also “unduplicate” clients across all services and geographic regions. This provides a more accurate picture of how many people are truly seeking care through services provided by Ryan White Title II.

Limitations: The Tennessee CAREWare data are provided or downloaded on a monthly basis; therefore, it is not a “real time” or web-based data collection system. In addition, the customized fields established for Tennessee CAREWare make future versions of this database provided by HAB/HRSA incompatible with the system the HIV/AIDS Program has developed. The data captured in Tennessee CAREWare also cannot be generalized to all HIV-infected persons living in this state, since it only collects data on persons who: (1) know their HIV serostatus; (2) are not eligible for health coverage through private insurance or Tennessee TennCare; (3) are currently seeking care and treatment services through Ryan White Title II-funded providers; and (4) are financially eligible to receive services. Historically, the population data that are captured in the Tennessee CAREWare data base has comprised approximately 30% of those known to be living with HIV/AIDS in the state.

APPENDIX B: GLOSSARY OF TERMS

AIDS: AIDS stands for acquired immunodeficiency syndrome. An HIV-infected person receives a diagnosis of AIDS after developing one of the CDC-defined AIDS indicator illnesses (see *opportunistic infection*) or on the basis of certain blood tests (i.e., having a CD4+ count of less than 200 or a CD4+ percent of less than 14). A positive HIV test result does not mean that a person has AIDS.

Antiretroviral therapies (ART): Antiretroviral therapies are anti-HIV treatments designed to reduce the levels of HIV in a person's body.

Bias: Bias occurs when there is systematic error in data that leads to results that do not represent the true findings. For example, if individuals feel uncomfortable about reporting that they have engaged in high-risk behaviors, then these behaviors will be systematically under-reported. Consequently, conclusions about the occurrence of such behaviors would be considered "biased."

CDC: The Centers for Disease Control and Prevention (CDC), within the U.S. Department of Health and Human Services, is the lead federal agency for protecting the health and safety of the people of the United States. CDC accomplishes its mission through developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve public health in the U.S. The CDC provides the majority of the funding for HIV prevention and HIV surveillance activities in Tennessee.

Denominator: The denominator is the lower portion of a fraction used to calculate a rate or ratio. For example, in the ratio $\frac{3}{4}$, four is the denominator.

Epidemiology: Epidemiology is considered to be the study of how diseases or health conditions are distributed in a population. Consequently, an epidemiologist may analyze

public health data to determine how a disease is transmitted and to recommend interventions, to identify segments of a population at risk for acquiring a disease, or to monitor disease trends and predict the future course and impact of a disease.

Exposure categories: In order to monitor how HIV is being transmitted, HIV/AIDS cases are classified into one of several exposure (risk) categories developed by the CDC:

- Men who have sex with men (MSM) refer to men who report having had sexual contact with other men, i.e., homosexual or bisexual contact.
- Injection drug user (IDU) cases are those who report ever using drugs that require injection. While it may be valuable to know that a person has used illicit drugs through other routes, this information would not be enough to classify a case as IDU.
- High-risk heterosexual contact (HRH) cases have reported heterosexual contact with a partner who is at increased risk for HIV infection, i.e., a homosexual or bisexual man or an IDU, or with a partner with documented HIV infection.
- Hemophilia/Transfusion/Transplant cases are those who report having received a transfusion of blood or blood products prior to 1985.
- Perinatal HIV cases are cases of HIV infection in children resulting from transmission from an HIV-positive mother.
- Unspecified or “No identified risk (NIR)” cases are those cases who have no reported history of exposure at the time of the publication. This category includes persons for whom the surveillance protocols to document risk behavior information have not yet been completed, persons whose exposure history is incomplete because they have died, persons who have declined to disclose their risk behavior or who deny any risk behavior, and persons who do not know the HIV status or risk behaviors of their sexual partners.

HAART: Highly Active Antiretroviral Therapy (HAART) refers to aggressive anti-HIV treatments that usually include a combination of protease and reverse transcriptase

inhibitors, which interrupt the HIV life cycle, and whose purpose is to reduce a person's viral load to undetectable levels.

HIV: HIV is an acronym for “Human Immunodeficiency Virus,” which is the virus that causes AIDS. A person who has contracted the virus is said to be HIV-positive or HIV-infected.

Incidence: Incidence refers to the number of new cases of a disease that occur in a population during a specified time period, usually a year. Even though HIV data are often presented as “new cases of HIV,” these data do not represent new infections (true HIV incidence), because a person may not be tested for HIV in the same time period that he or she became infected. On the other hand, incidence can be presented for diseases (e.g., some STDs). These diseases have clear symptoms that are detectable when a person becomes infected, and which cause a person to be tested or to seek treatment shortly after infection.

Numerator: The numerator is the upper portion of a fraction used to calculate a rate or ratio. For example, in the ratio $\frac{3}{4}$, three is the numerator.

Opportunistic infection (OI): Infection with HIV can weaken a person's immune system to the point that it has difficulty fighting off certain infections. These types of infections are known as "opportunistic" infections because they take the opportunity a weakened immune system gives to cause illness. Some examples of opportunistic infections are *Pneumocystis carinii* pneumonia (PCP) and Kaposi's sarcoma (KS). Opportunistic infections (OIs) are considered to be CDC-defined AIDS indicator illnesses, which means that an HIV-infected person receives a diagnosis of AIDS after developing one of them.

Perinatal: The word “perinatal” means “around birth” and is used to describe events that occur during labor and birth, and immediately following delivery. When “perinatal” is used to describe HIV transmission, however, this word applies more broadly and

describes any time that a mother may pass HIV to her child – either while she is pregnant, during birth, or through breast-feeding.

Prevalence: Prevalence refers to the total number of persons with a specific disease of condition at a given time. HIV prevalence data are generally presented as “persons living with HIV.” HIV prevalence data provided by HIV surveillance programs will underestimate the true HIV prevalence because HIV-infected persons who have not yet been tested or reported to the health department will not be included.

Proportion (percentage): A proportion is a type of ratio in which the numerator is included in the denominator. Because the numerator is a subset of the denominator, a proportion can be thought of as a ratio of a “part” to the “whole.” A proportion is usually expressed as a percentage.

Rate: A rate is a special type of ratio that includes a specification of time. In epidemiology, rates express the probability or risk of disease or other events in a defined population over a specified period of time, often one year.

Ratio: A ratio is the value obtained by dividing one quantity by another. For example, the number $\frac{3}{4}$ is a ratio and can be expressed verbally as “three divided by four.” Both rates and proportions are specific examples of ratios.

Reporting delay: Reporting delay refers to the time lag between when a new case of HIV or AIDS is first diagnosed and when that case is reported to the health department. Currently in Tennessee, 86% of HIV cases and 87% of AIDS cases are reported to the HIV/AIDS Surveillance Program within six months of being diagnosed with HIV or AIDS. Because of reporting delays, surveillance estimates of cases diagnosed in recent time periods will underestimate the actual number of cases that were diagnosed in those time periods. Consequently, data for recent time periods are adjusted to account for the anticipated number of cases diagnosed but not yet reported. For AIDS cases, the HIV/AIDS Reporting System (HARS) was used to generate reporting delay fractions. For

HIV cases, multiple years of data were reviewed to create estimates of the percentage of cases that were reported within specified periods of time following diagnosis of HIV infection (e.g., 1 year, 2 years). The estimates were then adjusted upward to account for the reporting delay.

Ryan White CARE Act: The Ryan White Comprehensive AIDS Resources Emergency Act was created to provide federal assistance to increase the availability of primary health care and support services for persons living with HIV disease, to increase access to care for underserved populations, and to improve the quality of life for those affected by HIV. The CARE Act was first enacted by Congress in 1990 and was reauthorized in 1996 and 2000.

HRSA implements the CARE Act and directs assistance through the following channels:

- Title I provides support to Eligible Metropolitan Areas (EMAs) with the largest numbers of reported AIDS cases, to meet emergency service needs of persons living with HIV;
- Title II provides support to all States and Territories to improve the quality, availability, and organization of health care and support services for persons living with HIV and their families;
- Title III supports outpatient early intervention HIV services through funding to public and private nonprofit entities;
- Title IV funds public and private nonprofit entities to conduct projects to coordinate services to children, youth, women, and families with HIV/AIDS; and
- Part F provides support for Special Projects of National Significance (SPNS) to develop and evaluate innovative models of HIV/AIDS care, for AIDS Education and Training Centers (AETC) to conduct education and training for health care providers, and for the HIV/AIDS Dental Reimbursement Program to assist with providing oral health services to HIV-infected patients.

Surveillance: In a public health context, surveillance refers to the intentional collection of data on diseases or other important health conditions in order to monitor where the condition occurs and to determine the risk factors associated with the condition.

Testing (confidential): In Tennessee, all HIV tests performed in publicly funded CTS are confidential. All confidential HIV-positive test results are reported to the health department where the information is maintained under the strictest security and confidentiality measures. Persons who are tested confidentially provide their names when taking the HIV test; this ensures that they may be linked to services and care if positive.

APPENDIX C: LIST OF ACRONYMS

AETC:	AIDS Education and Training Centers
ART:	Antiretroviral Therapy
BRFSS:	Behavioral Risk Factor Surveillance System
CADR:	CARE Act Data Report
CARE:	Comprehensive AIDS Resources Emergency Act
CBO:	Community-Based Organization
CDC:	Centers for Disease Control and Prevention
COE:	Centers of Excellence
CTS:	Counseling and Testing System
FPL:	Federal Poverty Level
HAART:	Highly Active Antiretroviral Therapy
HAB:	HIV/AIDS Bureau
HARS:	HIV/AIDS Reporting System
HDAP:	HIV/AIDS Drug Assistance Program
HIT:	Health Information Tennessee
HOPWA:	Housing Opportunities for People with AIDS
HRH:	High-Risk Heterosexual
HRSA:	Health Resources and Services Administration
IDU:	Injection Drug User
KS:	Kaposi's Sarcoma
MSA:	Metropolitan Statistical Area
MSM:	Men who have Sex with Men
NCCP:	National Center for Children in Poverty
NCHS:	National Center for Health Statistics
OI:	Opportunistic Infection
OMB 15:	Office of Budget and Management Directive 15
PCP:	<i>Pneumocystis carinii</i> Pneumonia
SPNS:	Special Projects of National Significance
STD:	Sexually Transmitted Disease
TOADS:	Tennessee Outcomes for Alcohol and Drug Services
YRBS:	Youth Risk Behavior Survey
ZDV:	Zidovudine

APPENDIX D: MAP OF TENNESSEE

